

Caregiving Experiences of South African Mothers of Adults with Intellectual Disability Who Display Aggression: Clinical Case Studies

Thesis presented for the Degree of
DOCTOR OF PHILOSOPHY
in the Department of Psychiatry and Mental Health

UNIVERSITY OF CAPE TOWN

August 2016

by

OCKERT COETZEE

Student number: CTZJAC010

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

ACKNOWLEDGEMENTS

I would like to thank the following persons who assisted me with this project:

My supervisors, Prof Colleen Adnams and Prof Leslie Swartz.

Nashareen – for your support, love and encouragement.

The kids: Mikayla, Clarissa and Ethan.

My parents and siblings.

A special word of thanks to Dr Charlotte Capri for all her support and help.

This project would not have been possible without the assistance and input from the following people: Elsie Breedt, Zaida Frank, Dr Elisa Galgut, Jacqueline Gamble, Siyabulela Mkabile, Dr Peter Smith, Caren van Houwelingen and Kim Windell. Thank you!

My colleagues at work.

Lastly, but most importantly, the participants of this study: Thank you so much for sharing your caregiving experiences and personal narratives.

This study was financially supported by the Vera Grover Trust Fund.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	i
TABLE OF CONTENTS	ii
LIST OF TABLES	viii
LIST OF ABBREVIATIONS AND ACRONYMS	ix
ABSTRACT	xii
CHAPTER ONE: LITERATURE REVIEW	1
1.1 Definition and Description of Psychological Concepts that Describe Maternal Psychological Well-being	1
1.1.1 Introduction	1
1.1.2 Definition of parental stress, its associated concepts, and symptoms of maternal depression	2
1.1.3 Theoretical models of parental stress and coping	4
1.1.4 Conclusion	10
1.2 Social Variables and the Psychological Well-Being of Mothers of Children who have Developmental Disabilities	11
1.2.1 Introduction	11
1.2.2 The relationship between social factors and maternal well-being among parents of children who have DD	11
1.2.3 Mental health services for children and adolescents who have ID and reside in LAMI countries	15
1.2.4 Research outcomes in LAMI countries: Social factors that could contribute to parental stress among parents of children who have ID	17
1.2.5 Intellectual disability in South Africa: Social factors	18
1.2.6 Conclusion	21
1.3 The Psychological and Physical Well-Being of Parents of Children who have ID	22
1.3.1 Introduction	22
1.3.2 Ageing parents and the accumulation of stressful caregiving experiences: The role of developmental considerations	23
1.3.3 The relationship between cognitive variables and parenting stress	25
1.3.4. Maternal depressive symptoms	32
1.3.5 Maternal anger	37
1.3.6 Positive aspects of parenting when raising a child who has ID	38
1.3.7 The physical well-being of mothers whose children have ID	40
1.4 The Behavioural Difficulties of the Child	51

1.4.1 Introduction	51
1.4.2 “Behaviour that challenges us” – the phenomenon of CB in services for people who have ID	52
1.4.3 The treatment of problem behaviour	62
1.5 Coping with Stressful Caregiving Demands.....	70
1.5.1 Introduction	70
1.5.2 The Folkman and Lazarus Process Model of Coping.....	72
1.5.3 Recent findings on available coping resources and strategies used by mothers of children who have ID.....	75
1.5.4 Parental reports on the use of formal and informal support as coping strategies.....	84
1.6 The Use of Cognitive-Behavioural Therapy with Parents of Children who have Intellectual Disability.....	85
1.6.1 Psychological intervention programmes for distressed parents of children who have ID and behavioural difficulties.....	94
1.6.2 Psychotherapy process research with families of children who have DD	98
1.7 Towards a Research Agenda: A Critical Appraisal of the Literature Review.....	103
CHAPTER TWO: RESEARCH METHODOLOGY	106
2.1 Research Question	106
2.1.1 The reformulated research question	106
2.1.2 The use of CBT was not invalidated by the reformulated research question	107
2.2 Study Design and Research Methodology.....	107
2.2.1 Defining case study research	107
2.2.2 The advantages of case studies	107
2.2.3 Criticism against case study research from different paradigmatic perspectives: The potential methodological pitfalls of poorly-designed case studies.....	110
2.2.4 Balancing the strengths of case study research against legitimate criticism: The study's rationale for using a series of single cases	113
2.2.5 Positioning the current study within contemporary psychotherapy case study research: The different forms of case studies	114
2.2.6 The study's use of a mixed-method case design.....	118
2.2.7 Strategies that were employed to enhance qualitative rigour and improve the quality of the study design	120
2.2.8 The adoption of action research to ground the exploratory agenda of case-based research	125

2.3	Characteristics of Participants	127
2.3.1	Number of participants	127
2.3.2	Location of research	127
2.3.3	The recruitment process, inclusion and exclusion criteria	128
2.3.4	Vulnerability and informed consent: parent and child.....	130
2.4	Recruitment, Enrolment and Informed Consent from Parents and their Children	130
2.5	Research Procedures and Data Collection	133
2.5.1	Use of psychometric tests in the South African context.....	133
2.5.2	Qualifications of researcher	134
2.5.3	The protocol of psychometric tests employed in research	134
2.5.4	Design of cognitive-behavioural intervention	142
2.5.5	Semi-structured interviews before and after completing psychotherapy	143
2.6	Data Safety and Monitoring Plan	149
2.7	Data Reduction and the Analysis of Data	149
2.7.1	The process of data reduction in the study	149
2.7.2	Strategies that were employed to analyse the third level of data	152
2.7.3	The analysis of data in each case study: A recursive, iterative and reflexive process	153
2.7.4	The analysis of thematic content within each case and between cases: The study's thematic analysis of intra-subject variation and the transferability of themes across cases	158
CHAPTER THREE: THEMATIC ANALYSIS OF SINGLE CASES AND INTEGRATION WITH TEST RESULTS.....		159
3.1	The first case study: Patricia*	159
3.1.1	Introduction	159
3.1.2	Case formulation.....	161
3.1.3	Narratives of psychotherapy sessions.....	164
3.1.4	Interview after psychotherapy had been terminated	190
3.1.5	Themes that emerged from thematic analysis	192
3.1.6	Psychometric test results	196
3.1.7	Discussion	199
3.2	The Second Case Study: Linda	203
3.2.1	Introduction	203
3.2.2	Case formulation	205

3.2.3 Narratives of psychotherapy sessions.....	207
3.2.4 Interview after psychotherapy had been terminated	228
3.2.5 Themes that emerged from thematic analysis	229
3.2.6 Psychometric test results	234
3.2.7 Discussion	238
3.3 The Third Case Study: Jeanette	246
3.3.1 Introduction	246
3.3.2 Case formulation	247
3.3.3 Narratives of psychotherapy sessions.....	250
3.3.4 Interview after psychotherapy had been terminated	264
3.3.5 Themes that emerged from thematic analysis	265
3.3.6 Discussion	271
3.4 The Fourth Case Study: Hadil.....	274
3.4.1 Introduction	274
3.4.2 Case formulation	275
3.4.3 Narratives of psychotherapy sessions.....	278
3.4.4 Interview after psychotherapy had been terminated	295
3.4.5 Themes that emerged from thematic analysis	297
3.4.6 Psychometric test results	301
3.4.7 Discussion	305
3.5 The Fifth Case Study: Marlene	310
3.5.1 Introduction	310
3.5.2 Case formulation	311
3.5.3 Narratives of psychotherapy sessions.....	315
3.5.4 Interview after psychotherapy had been terminated	328
3.5.5 Themes that emerged from thematic analysis	330
3.5.6 Psychometric test results	334
3.5.7 Discussion	337
3.6 The Sixth and Last Case Study: Sarah.....	341
3.6.1 Introduction	341
3.6.2 Case formulation	342
3.6.3 Narratives of psychotherapy sessions.....	343
3.6.4 Interview after psychotherapy had been terminated	363
3.6.5 Themes that emerged from thematic analysis	365

3.6.6 Psychometric test results	369
3.6.7 Discussion	373
CHAPTER FOUR: THEMATIC SYNTHESIS – RECURRENT THEMATIC CONTENT AND THE TRANSFERABILITY OF EMERGING THEMES ACROSS DIFFERENT CASES.....	380
4.1 Depressive Symptoms and the Manifestation of Guilt and Self-blame	380
4.1.1 Introduction	380
4.1.2 “ <i>Stuck in a rut</i> ”: Depressive symptoms as a result of caregiving stressors that persisted over the course of time	380
4.1.3 “ <i>I am at fault</i> ”: The potency of earlier parental experiences on here-and-now assertions of guilt, shame and self-blame	387
4.1.4 The use of cognitive-behaviour therapy to reduce symptoms of depression	397
4.1.5 Clinical implications: Towards a distinction between depressive symptoms and parental stress	400
4.2 Exploring Stressful Caregiving Demands and the Child’s Behavioural Difficulties: Parental Stress and its Associated Constructs	403
4.2.1 Introduction	403
4.2.2 Parental stress and the child’s behavioural difficulties: <i>In situ</i> distress, worry and apprehension	404
4.2.3 Other cognitive factors that were linked with parental stress	412
4.2.4 Conclusion.....	418
4.3 Parental Stress and Maternal Depressive Symptoms in the Context of Other Health Issues and Stressful Social Factors	427
4.3.1 Introduction	427
4.3.2 Maternal mental health and the formative influences that shaped contemporary beliefs	430
4.3.3 Family tension, financial hardship and inadequate or inappropriate family support.....	434
4.3.4 Maternal physical and mental health and other psychological problems that warranted clinical consideration.....	442
4.3.5 Conclusions and clinical implications	451
4.4 The Unavailability or Inadequacy of Formal Support Services in the Public Sector	452
4.4.1 The clinical implications of findings	454
CHAPTER FIVE: CONCLUSION AND RECOMMENDATIONS.....	455
5.1 Concluding Remarks	455
5.2 The Use of a Case-Based Design: Methodological Strengths and Limitations and Suggestions for Future Research.....	463

REFERENCES	469
APPENDICES.....	513
Appendix A: The Interpretation of Maternal Experience from the Therapist's Perspective: An Epistemological and Paradigmatic Positioning of the Study	513
Appendix B: Consent Form to Participate in Research – Mothers.....	567
Appendix C: Consent Form – Children of the Mothers who Participated in the Study.....	571
Appendix D: Ethics Approval from the Health Sciences Research Ethics Committee – University of Cape Town	582
Appendix E: Number of Omissions and Additions of Sentences and Words as Assessed by a Third Party	583
Appendix F: Example of Data Reduction and Coding as Part of the Thematic Analysis- A Rough Draft of Codes that Were Generated From the Psychotherapy Sessions with Patricia	584

LIST OF TABLES

Table 1: Summary of Studies that Examined Cognitive Variables of Parenting Stress Among Parents Whose Children have ID.....	30
Table 2: CBT and Parental Stress.....	87
Table 3: Psychotherapy Studies: Distressed Parents of Children and Adults who have Developmental Disability and Behavioural Difficulties.....	95
Table 4: Strategies that were Used to Enhance the Qualitative Rigour of this Study.....	122
Table 5: Summary of Psychometric Tests Used in the Study.....	133
Table 6: Braun and Clarke's (2006) Six Phases of Thematic Analysis.....	154
Table 7: Number of Psychotherapy Sessions, Psychometric Assessments and Individual Interviews in Each Case Study.....	155

LIST OF FIGURES

Figure 1: Hastings' model of parenting stress.....	7
Figure 2: The ABC model in behaviour therapy.....	9
Figure 3: The study design of each case.....	119

LIST OF ABBREVIATIONS AND ACRONYMS

ACTH	Adrenocorticotrophic Hormone
ADOS II	Autism Diagnostic Observation Schedule, Second Edition
ADHD	Attention-Deficit Hyperactivity Disorder
ADL	Activities of Daily Living
AED	Anti-Epileptic Drugs
AIDS	Acquired Immune Deficiency Syndrome
APA	American Psychiatric Association
ASD	Autistic Spectrum Disorder
BDI-II	Beck Depression Inventory, Second Edition
BPT	Behavioural Parent Training
CB	Challenging Behaviour
CBT	Cognitive-Behaviour Therapy
CRH	Corticotrophin-Releasing Hormone
DC-LD	Diagnostic Criteria for Learning Disabilities
DD	Developmental Disabilities
DSM V	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
ER	Emergency Room

FASD	Fetal Alcohol Spectrum Disorder
FMR1 premutation	Fragile X Mental Retardation 1 Premutation
FSI	Family Systems Intervention
GNP	Gross National Product
HIV	Human Immunodeficiency Virus
HPA Axis	Hypothalamic-Pituitary-Adrenal Axis
HS	Hope Scale
ID	Intellectual Disability
IPA	Interpretative Phenomenological Analysis
IPV	Intimate Partner Violence
LAA	Low-Arousal Approach
LAMI countries	Low and Middle Income Countries
MCT	Multicomponent Training
OPD	Out-Patient Department
OT	Occupational Therapy/Therapist
PAS-ADD	Psychiatric Assessment Schedules for Adults with Developmental Disabilities
PLOC	Parental Locus of Control Scale
PSI-SF	Parenting Stress Index - Short Form

PSOC	Parenting Sense of Competence Scale
RCT	Randomised Controlled Trial
REBT	Rational-Emotive Behaviour Therapy
RP	Retinitis Pigmentosa
SEP	Socio-Economic Position
TEACCH	Counseling and Treatment and Education of Autistic and related Communication-Handicapped Children
WAYS	Ways of Coping Questionnaire

ABSTRACT

Background: Adults who have an intellectual disability (ID) often continue to live with their parents long after their siblings have left home. While an increasing body of research has described positive parental experiences, research has also found that parents of adults who have ID and behavioural difficulties are more vulnerable to develop parental stress and depression. Aggression is one of the most difficult forms of problem behaviours to manage and could have a negative impact on the parent-child relationship, the child's social inclusivity and the psychological well-being of parents.

Method: A case-based psychotherapy design was used to explore maternal experiences among mothers of adults with ID and aggression who access a specialised mental health service in Cape Town. Psychotherapy was used with six participants to attempt to reduce parental stress and other negative psychological states. In an area of research that has received scant attention in South Africa, the study extensively describes the psychotherapy process and the role of contextual factors in the lives of the participating mothers.

The study used a mixed methods design which included psychometric measurements that were conducted at various intervals of intervention. Thematic analysis was used in all the case studies and interviews were scheduled before and after completing psychotherapy. External credibility was enhanced through the use of different qualitative strategies that included peer supervision and reflexivity.

Findings: Besides elevated parental stress, the majority of participants presented with symptoms of depression and other mental health problems that varied according to their individual profiles. Although parental stress showed a discernible

relationship with the child's behavioural difficulties, other significant life stressors contributed to maternal stress and depressive symptoms. Psychotherapy produced only modest improvement of parental stress among some of the participants. However, therapeutic input appeared to be more effective in reducing depressive symptoms among the majority of mothers. Critical reflection and discussion are centred on the clinical implications and meaning of findings on a psychological level.

Keywords: caregiving experiences, parental stress, depression, psychotherapy, intellectual disability, aggression

CHAPTER ONE: LITERATURE REVIEW

1.1 Definition and Description of Psychological Concepts that Describe Maternal Psychological Well-being

1.1.1 Introduction

The psychological well-being of parents of children who have ID has been extensively studied (Blacher & Hatton, 2001; Blacher, Neece, & Paczkowski, 2005; Chou, Pu, Fu, & Kröger, 2010; Cuskelly, 2006; Dillenburger & McKerr, 2010; Emerson & Hatton, 2009; Gallagher & Whiteley, 2013; Hassall & Rose, 2005; Hastings & Beck, 2004; Haveman, Van Berkum, Reijnders, & Heller, 1997; C. Hill & Rose, 2009; Thompson, Kerr, Glynn, & Linehan, 2014; Woodman & Hauser-Cram, 2013). While most studies have focused on parents of children who have ID (Glidden, Billings, & Jobe, 2006; Hassall, Rose, & McDonald, 2005; Saloviita, Itälinna, & Leinonen, 2003; T. B. Smith, Oliver, & Innocenti, 2001; Woolfson, Taylor, & Mooney, 2010), a growing number of studies have also investigated parental well-being among parents of adults who have ID (e.g., Barker, Greenberg, Seltzer, & Almeida, 2012; Ben-Zur, Duvdevany, & Lury, 2005; Faust & Scior, 2008; Hatton et al., 2010; McConkey, 2005; Heller, Caldwell, & Factor, 2007).

Most of the studies in the ID family research domain have described negative psychological states such as parental stress, caregiving strain or depressive symptoms (Hastings, 2002; Singer, Ethridge, & Aldana, 2007). Increasingly, studies have also focused on positive parental experiences (Blacher, Begum, Marcoulides, & Baker, 2013; Griffith & Hastings, 2013; Lloyd & Hastings, 2009).

1.1.2 Definition of parental stress, its associated concepts, and symptoms of maternal depression

Parenting stress is defined as “the experience of distress or discomfort that results from demands associated with the role of parenting” (Deater-Deckard, 1998, as cited in Hayes & Watson, 2013, p. 629).

Stress results from individual appraisals of existing personal resources as being inadequate or failing to meet environmental demands that are potentially harmful, threatening or challenging (Folkman, 1984).

Hayes and Watson (2013) contend that family research should distinguish parental stress from other negative maternal states such as depression, anxiety and anger: parental stress relates to distressing aspects of parenting while concepts such as depression and anger have aetiological bases that generally surpass the relatively narrow confines of parenting.

In this study, *depression* or *maternal depression* denotes symptoms of unipolar mood disorder as stipulated in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM V) (American Psychiatric Association (APA), 2013; Bailey, Golden, Roberts, & Ford, 2007).

The consequences of sustained parental stress may also include negative psychological states such as depression and subjective accounts of poor physical health (Chou et al., 2010; Hayes & Watson, 2013).

Burnout is widely used in research to describe negative caregiving experiences among paid carers and professionals employed in services for people who have ID (Skirrow & Hatton, 2007; B. A. Smith & Kaye, 2009). Burnout is characterised by “a

state of physical, emotional and mental exhaustion that occurs when workers feel overburdened by the demands of long-term involvement in emotionally demanding situations” (Skirrow & Hatton, 2007, p. 132).

In this study, descriptions of maternal fatigue resort under depression or dysthymia, provided that other diagnostic criteria of mood disorder were met (APA, 2013). In order to draw clear distinction between distressed parents and the negative experience of burnout among paid carers, the use of the concept of "burnout" will be avoided in the study (Andronicos, 2007; Skirrow & Hatton, 2007).

ID family research has sometimes described distressing caregiving encounters as contributing to a family's burden of care (e.g., Cummins, 2001; Maes, Broekman, Dosen, & Nauts, 2003). Burden of care also refers to similar experiences in families of people who have a mental illness such as schizophrenia (e.g., Awad & Voruganti, 2008).

The application of this concept in family research has been criticised because it conceptually covers negative family experiences across a broad range of predominantly negative family outcomes (Awad & Voruganti, 2008). Encompassing psychological, physical and economic burdens on the family, a perceived high burden of care could eventuate in “subtle but distressing notions such as shame, embarrassment, feelings of guilt and self-blame” (Awad & Voruganti, 2008, p. 151).

Caregiver strain construes challenging caregiving situations as "demands, responsibilities, difficulties, and negative psychic consequences of caring for relatives with special needs” (Brannan, Heflinger, & Bickman, 1997, as cited in Kenny & McGilloway, 2007, p. 222). Objective strain refers to observable events and situations that are associated with the child’s behaviour. Subjective strain

describes internalised feelings and thoughts as well as externalised states that are usually representative of negative feelings towards the child and the child-parent relationship (Kenny & McGilloway, 2007).

This study attempted to describe specific caregiving events and corresponding cognitive and affective maternal reactions on an individual level. The use of terms such as burden of care and strain was not widely employed.

1.1.3 Theoretical models of parental stress and coping

A number of coping models have been widely used in family research of people who have ID to describe the manner in which families deal with distressing caregiving events (Glidden et al., 2006; Glidden & Natcher, 2009; Kelso, French, & Fernandez, 2005; Kim, Greenberg, Seltzer, & Krauss, 2003; Mak & Ho, 2007; Neely-Barnes & Dia, 2008; Seltzer, Greenberg, & Krauss, 1995; Woodman & Hauser-Cram, 2013).

The study has used the process model of stress and coping to explore maternal coping strategies and resources to deal with distressing aspects of caregiving.

Developed by Richard Lazarus and Susan Folkman, the process model of stress and coping is described as "a process-oriented approach to coping [which] is directed toward what an individual actually thinks and does within the context of a specific encounter and how these thoughts and actions change as the encounter unfolds" (Folkman & Lazarus, 1988, p. 2).

A separate section of the literature review covers the central tenets and findings of research that has been conducted to examine the ways in which parents of children who have ID cope with distressing caregiving situations. The association between parental stress and coping will be unpacked in this chapter.

Parenting stress has received extensive attention in family research outside the ID field (Abidin, 1995; Johnston & Mash, 1989; McCubbin & Patterson, 1982).

Johnston & Mash (1989) linked elevated levels of parental stress with specific constructs that were grouped under the domains of child, parent and environmental characteristics.

Child characteristics include behavioural difficulties, the person's level of ID and adaptive abilities (C. Hill & Rose, 2009). Parent characteristics refer to a parent's psychological well-being and physical health (Hassall, Rose, & McDonald, 2005; C. Hill & Rose, 2009). *Environmental characteristics* recognise social constructs such as socio-economic position and hardship as potential moderators in the relationship between parental stress and the child's behaviour (Johnston & Mash, 1989).

Whereas the Johnston and Mash model demarcates contributing factors to parental stress into three discrete categories, two other theoretical models place more emphasis on the family's ability to process distressing caregiving events (Hassall et al., 2005; C. Hill & Rose, 2009).

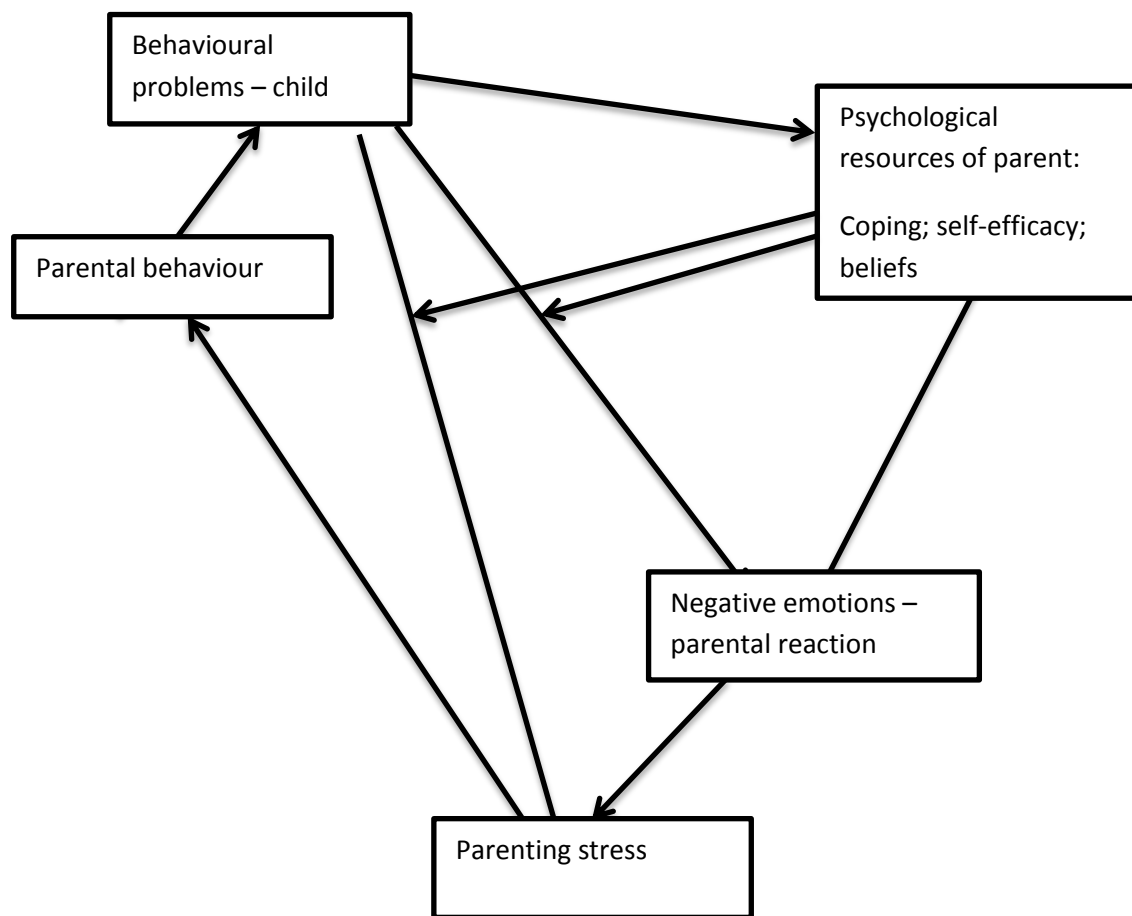
The first theoretical framework, the double ABC-X model, describes family distress as a crisis (X) stemming from the family's processing of stressful events (A). The processing of adverse caregiving situations will rely on different family strengths (B) and perceptions of the distressing events (C) (Brannan & Heflinger, 2001; McCubbin & Patterson, 1982; McStay, Trembath, & Dissanayake, 2014; Saloviita et al., 2003).

The process model of coping describes parental stress as the result of primary appraisals that construct adverse caregiving events as potentially harmful, challenging or threatening. Secondary appraisals consider such events as

"exceeding" or *"taxing"* available coping resources to deal effectively with the distressing situation (Folkman, 1984, p. 840).

Hastings (2002) applied the core principles of the double ABC-X model and process model of coping to formulate a theoretical model that conceptualises a bidirectional relationship between the child's behavioural problems and parental stress among parents of children who have ID. As presented in Figure 1, Hastings (2002) also explored the potential relationship between parental stress and parental behaviours towards their children. Parental behaviours were conceptually linked with the child's behavioural difficulties (Hastings, 2002). For example, sustained elevations of parental stress following repeated episodes of the child's aggression may result in stringent verbal reprimands (parental behaviour) that increases the child's agitation, thereby resulting in continued irritability and aggression (child's behaviour)

Figure 1. Hastings' model of parenting stress



A growing body of research has associated the child's behavioural difficulties with different negative psychological states among parents of children who have ID (Blacher & McIntyre, 2006; Gallagher & Whiteley, 2013; Ha, Hong, Seltzer, & Greenberg, 2008; Hassall et al., 2005; C. Hill & Rose, 2009; Kim et al., 2003; McIntyre, Blacher, & Baker, 2002; Minnes, Woodford, & Passey, 2007; Pruchno & Meeks, 2004; Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011; Woodman & Hauser-Cram, 2013).

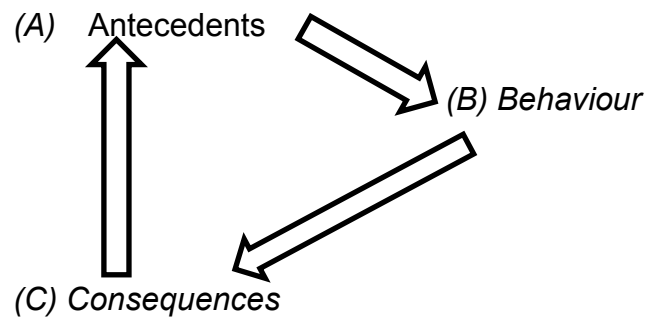
Research has also established a relationship between parenting stress and the children's behavioural difficulties across various genetic syndromes and psychiatric disorders such as Cornelia de Lange syndrome (e.g., Richman, Belmont, Kim, Slavin & Hayner, 2009), autism (e.g., Benson & Karlof, 2009), epilepsy (Thompson, Kerr, Glynn, & Linehan, 2014), ID dual diagnoses (e.g., Maes et al., 2003) and combinations of medical and mental health concerns among persons who have ID (e.g., Crocker, Prokić, Morin, & Reyes, 2014).

As illustrated in Figure 1, Hastings' (2002) model of parental stress postulates that the relationship between maternal stress and the child's behavioural problems is moderated by the psychological resources of parents that include cognitive variables such as self-efficacy and specific beliefs about the child's behaviour.

In addition to cognitive variables, the process of parental coping has a mediating and moderating influence on reciprocal relationships between parental stress, parenting behaviours and the child's problem behaviours. Bidirectional relationships also imply that parental behaviour towards the child may possibly reinforce their offspring's behavioural problems (Hastings, 2002).

To argue this point further, the classical ABC model of behaviour therapy is presented in Figure 2 (Spiegler & Guevremont, 2003).

Figure 2. The ABC model in behaviour therapy



Different antecedents comprising setting events or prerequisite triggers (A) activate discrete behaviours (B). The consequences of such behaviours (C) in turn reinforce future antecedents (A) that maintain similar behaviours (B) in a cyclical manner (Spiegler & Guevremont, 2003).

The ABC model could be applied to Hastings's (2002) theory of caregiving stress by means of the following fictional example:

A child's display of verbal aggression (A) may result in parental stress (B) that leads to coercive parenting practices. The parent therefore forcefully demands that the child should stop swearing (C1). Increased attention, albeit in a negative manner, constitutes another consequence (C2) that is thereby stratified with repeated expostulations to stop swearing (C1). In turn, attention (C2) reinforces future incidents of swearing as the child attempts to get attention from his parent with the use of socially unacceptable behaviour (A), which again would reinforce parental stress (B) in a cyclical manner.

The different models of parental stress provide useful theoretical frameworks to investigate parental stress and other psychological problems such as depression in mothers of children who have ID and behavioural difficulties.

1.1.4 Conclusion

The interchangeable use of different terms such as burden of care and caregiving strain to depict negative psychological states among families of persons who have ID has confounded results and prevented the replication of findings to some extent (Brannan & Heflinger, 2001). It is also problematic to indiscriminately use parental stress and maternal depressive symptoms when the latter could be accounted for by experiences that fall outside the parameters of parenting (Hassall et al., 2005; Hayes & Watson, 2013).

The remaining part of the first chapter will be divided into different sections: The next section of the literature review will describe the relationship between distal social factors and the psychological well-being of mothers whose children have ID.

The third section will explicate the psychological and physical well-being of mothers whose children have ID by focusing on the respective cognitive variables that mediate and moderate the relationship between parental stress and the child's behavioural difficulties. In addition, many studies have shown that maternal psychological well-being is linked with the physical well-being of mothers. Mothers of adults who have ID have also reported positive caregiving experiences.

In the fourth section, an outline of problem behaviours among adults who have ID will be provided owing to the study's focus on South African mothers of adults who have ID and aggression.

The fifth section covers the basic principles of Folkman and Lazarus's Process Model of Coping as applied to families of persons who have ID.

The last chapter will focus on cognitive-behaviour therapy. In addition, a selection of intervention studies in the intellectual disability family research field will be presented.

1.2 Social Variables and the Psychological Well-Being of Mothers of Children who have Developmental Disabilities

1.2.1 Introduction

As described earlier, the psychological model of Hastings (2002) highlights the role of cognitive variables and coping resources as mediators and moderators of maternal responses to their children's behavioural difficulties. The process model of coping and ABC-X model both revolve around the processing of distressing caregiving events in families of children and adults who have ID (Brannan & Heflinger, 2001; Kelso et al., 2005; McCubbin & Patterson, 1982; Saloviita et al., 2003).

In ID family research, coping models have been criticised for neglecting broader social factors such as socio-economic position (SEP) and poverty when investigating phenomena such as parental stress (Emerson, Hatton, Llewellyn, Blacher, & Graham, 2006; Hatton & Emerson, 2009).

1.2.2 The relationship between social factors and maternal well-being among parents of children who have DD

The relationship between parental distress and different social variables among families of children and adults who have ID has been explored in a number of recent studies (e.g., Blacher & Hatton, 2001; Eisenhower & Blacher, 2006; Emerson &

Llewellyn, 2008; Emerson et al., 2006; Emerson et al., 2010; Heller et al., 2007; T. B. Smith et al., 2001).

Emerson & Hatton's (2009) distinction between proximal and distal causes provides a more comprehensive and nuanced understanding of the complex interaction between different familial and psychological stresses. For example, associations between parenting stress and SEP are weakened by the presence of different neurological underpinnings such as profound ID and autism. Yet such proximal events should not detract from the potential role of relevant distal variables (Emerson & Hatton, 2009).

In line with Conger's stress model, ID family research has considered the role of human and social capital as having an influence on a parent's capacity to deal with adverse social circumstances, parental distress, family hardship and the child's behavioural difficulties (Emerson & Hatton, 2009).

Social capital refers to a person's connectivity and relationships with other family members, acquaintances and colleagues at work (Putnam, 1995). Human capital describes a person's skills and knowledge that were obtained at school or when the person pursued a tertiary qualification. These skills are employed in the labour market or when a person is problem-solving different life challenges (Agesa, Agesa, & Bongani, 2010).

A recent population-based comparative study investigated the association between discrete social factors and maternal well-being among British mothers of children with or without ID. Of the 6 954 participants, 514 had children who were diagnosed with ID.

Findings suggest that, taken together, low SEP, poverty, maternal characteristics and household composition fully accounted for lowered self-esteem and self-efficacy among a substantial proportion of mothers whose children had ID (Emerson et al., 2006).

Compared with mothers whose children did not have ID, the study found elevated levels of stress, poorer health (mental and physical), and unhappiness among mothers of children who have ID. Statistical difference between mothers with and without children who had ID was nullified once SEP, household composition and maternal health and level of education were controlled. On its own, SEP reduced differences between the two groups to non-significant levels (Emerson & Hatton, 2009; Emerson et al., 2006).

The study's methodological strengths included the large, representative sample size and use of multiple measurements of SEP. A possible limitation related to the lack of standardised assessment instruments to confirm the child's diagnosis of ID (Emerson & Hatton, 2009; Emerson et al., 2006).

Another large study with a sample of 4 983 children was conducted in Australia (Emerson & Llewellyn, 2008). It was found that mothers whose young children were at risk of developing disability had a higher prevalence of psychiatric disorder than mothers whose children were developing within normal developmental limits.

Elevated levels of parental stress were linked with the mother's mental health status, SEP, adverse life events and availability of social support. Poverty amongst children who were vulnerable to developing disability increased the probability of maternal distress by 50%. The relationship between poverty and maternal distress was mediated by lower health status and limited social and human capital. Remaining

risk factors of maternal distress were linked with the child's behaviour, social abilities and emotional development (Emerson & Llewellyn, 2008).

Mothers of children below the age of five were recruited. Interestingly, higher SEP moderated maternal unhappiness about the child having an ID (Emerson & Llewellyn, 2008).

The methodological strengths of the study included a large sample size and the use of rigorous evaluation methods to assess maternal psychopathology. The authors described the use of the children's weight and body mass index as methodological limitations. Moreover, future research should consider the use of comprehensive interviews about early childhood development and the use of recognised developmental assessments (Emerson & Llewellyn, 2008).

A third epidemiological study of 12 689 three-year old children was conducted in the UK. When compared with families without children who have ID, the families of children who have ID were significantly worse off on measurements of SEP, poverty and hardship (Emerson et al., 2010).

Socio-economic adversity and higher levels of psychiatric illness were also attributed to poorer personal capital that resulted from comparatively lower levels of education and lower remunerative work (Emerson et al., 2010).

The majority of family research in the ID field has been conducted in high-income countries (Einfeld et al., 2012; Emerson, Yasamy, & Saxena, 2012). It is conceivable that poverty and low social and human capital may moderate maternal distress to an even greater extent in low- and middle-income (LAMI) countries.

Although these countries have higher levels of relative and absolute poverty, they

are poorly represented in international research efforts and policy-making (Emerson et al., 2012; Shin & Nhan, 2009).

As measured by the Gini Index, South Africa, a higher middle-income country, has the second highest level of income inequality in the world. Approximately half of the population live in absolute or relative poverty (Adato, Carter, & May, 2006; World Bank, 2012). Poverty in itself constitutes a societal stressor that could adversely affect a person's psychological well-being (Wilkinson, 2005). A recent literature review highlighted the scarcity of applicable South African research about the role of social stressors among families of persons who are diagnosed as having an ID (Adnams, 2010).

A small number of studies that have focused on poverty and social inequality in LAMI countries, including South Africa, will now be presented. It will be argued that adverse social factors could in part cause higher levels of parental distress among mothers of children who have ID.

1.2.3 Mental health services for children and adolescents who have ID and reside in LAMI countries

The large population-based studies that were presented in the previous section have not been replicated in LAMI countries; and there are only a small number of studies that have investigated the role of social factors among families of people who have ID in LAMI countries (Emerson & Hatton, 2009).

Compared with a measured gross national product (GNP) of over \$37 000 per capita in high-income countries, people who live in LAMI countries have considerably less financial resources with GNP per capita averaging \$1 400 and \$6 000 (Emerson et al., 2012). In LAMI countries most families need to manage with fewer material

resources amidst higher levels of relative and absolute poverty. LAMI countries also experience almost ubiquitous shortfalls in public health spending. Family research of SEP and poverty within LAMI contexts is thus of common interest for different low-income nations (Emerson et al., 2012).

Systematic literature reviews have identified a small number of studies that have explored aspects of mental health care provision to children and adolescents who have ID in LAMI countries (Einfeld et al., 2012; Hastings, Robertson, & Yasamy, 2012; Robertson, Emerson, Hatton, & Yasamy, 2012; Robertson, Hatton, Emerson, & Yasamy, 2012).

An in-depth discussion of the findings goes beyond the focus of this study, but a brief overview of the recommendations of the reviews will direct attention to the focus areas of required research in LAMI countries.

One of the main findings across the four literature reviews was that intervention programmes and therapeutic initiatives for children and adolescents who have ID had generally been implemented in the absence of a strong evidence base of research (Hastings et al., 2012; Robertson, Emerson et al., 2012). It is conceivable that the lack of evidence-based treatments for behavioural difficulties among persons who have ID in LAMI countries may hamper the formal support services that distressed parents need to optimally manage their children's aggression.

When conducting evidence-based family research in poorly-resourced settings, it is also imperative that researchers are sensitive to local customs and cultural idiosyncrasies (Hastings et al., 2012).

All four literature reviews have highlighted the need to improve mental health services in LAMI countries for children, adolescents and their families (Einfeld et al., 2012; Hastings et al., 2012; Robertson, Emerson et al., 2012; Robertson, Hatton et al., 2012). Research initiatives and efforts to improve mental health services within LAMI countries such as South Africa should therefore consider the caregiving challenges of families of children and adults who have ID.

1.2.4 Research outcomes in LAMI countries: Social factors that could contribute to parental stress among parents of children who have ID

A number of studies have documented mental health problems and psychological distress among parents of children and adults who have ID (e.g., Gohel, Mukherjee, & Choudhary, 2011; Gupta & Kaur, 2010; John, 2012; Norizan & Shamsuddin, 2010; Osada et al., 2012).

For example, two studies have described increased levels of subjective parental strain among parents of children who have ID (Gupta & Kaur, 2010; Norizan & Shamsuddin, 2010). In an Indian study comprising a parental sample of 102, of whom 72 had children with ID, Gupta and Kaur (2010) have found that parents of children who have ID presented with significantly higher levels of physical and psychological stress than parents of children who did not have ID. Although the study's sample size comprised over a hundred participants, the following methodological weaknesses were identified:

- The study did not specify how the children were diagnosed with ID.
- The sample was selected from only three schools.
- The Quick Stress Assessment test was the only questionnaire used to measure parental stress (Gupta & Kaur, 2010).

A recent Vietnamese study measured parental stress among 225 mothers. It was found that mothers whose children had cognitive delay had less financial resources, lower levels of education and less informal support from family and friends when compared with mothers whose children did not have ID (Shin & Nhan, 2009). One of the strengths of the study related to the inclusion of a comprehensive demographic questionnaire to control socio-economic differences between the two groups. The selection of children who had cognitive delay was based on a teaching rating scale, the ABILITIES Index. Children were included in the study even when parents did not agree with teachers that their children had ID. The use of standardised measurements and clinical observation by qualified health care professionals would have strengthened the study design (Shin & Nhan, 2009).

While a number of studies have found that poverty led to increased social exclusion and familial and/or parental strain (e.g., Ajuwon & Brown, 2012), research also cited cultural variables as significant moderators of parenting stress and strained family relationships. Some of the studies on the Indian subcontinent and Far East found that mothers of girls who have ID had greater levels of distress due to perceived societal inequalities based on the gender of their children (e.g., Gupta & Kaur, 2010; John, 2012; Shin & Nhan, 2009).

1.2.5 Intellectual disability in South Africa: Social factors

The findings of a large epidemiological study that sampled 6 692 children who lived in an impoverished rural district in South Africa linked the development of mild ID among these children with the following variables: 1) poverty; 2) poor diet and nutrition; 3) inadequate “*intellectual stimulation*”; 4) medically unsupervised home-based child births; and 5) other aetiological factors such as maternal alcohol use during pregnancy and maternal health status with regard to the human

immunodeficiency virus (HIV) (Christianson et al., 2002, p. 46). The study included developmental screening by qualified paediatricians; and recognised neurodevelopmental assessment instruments were used to establish the presence of developmental disability (Christianson et al., 2002).

Another well-designed epidemiological study has found that some of the rural parts of the Western Cape have the highest rate of fetal alcohol spectrum disorder (FASD) in the world (May et al., 2005). Four teams screened all the first year elementary students in 12 of the selected district's 13 primary schools. Each team consisted of a United States dysmorphologist and a South African physician with specialised training in the clinical diagnosis of FASD. A total of 992 children were assessed a standard screening instrument that was developed by the United States Institute of Medicine. The researchers rated the prevalence of FASD among children who attended school in the district between 40.5 and 46.4 per thousand children (May et al., 2005).

There is mounting evidence to suggest that children who are HIV positive are at an increased risk of developing significant cognitive and neurodevelopmental delay. It is estimated that 5.38 million South Africans, or 10% of the total population, are HIV positive. The high rate of HIV-infection affects people across ethnicities and SEP, resulting in significant social and economic hardship (Lund, Kleintjes, Kakuma, & Flisher, 2010).

Apart from poverty and healthcare epidemics, the role of cultural influences has also had a bearing on perceptions regarding ID in South Africa. A recent study found that African parents of children who have ID commonly used the services of traditional healers as treatment options for their children (Kromberg et al., 2008). The majority

of a 100 traditional healers reported that they generally lacked sufficient grounding and knowledge about the aetiology of ID to assist the parents who make use of their services (Kromberg et al., 2008).

In a literature review, it was also suggested that people who have ID who live in sub-Saharan Africa often face stigma from health care professionals and traditional healers (Njenga, 2009). In one study that used structured interviews with 60 participants, South African parents of children who have ID had described persistent public transport difficulties and stigmatising attitudes of taxi drivers towards children who have ID (Masasa & Irwin-Carruthers, 2005).

Even though South Africa is the only country in Africa with inscribed constitutional rights for people who have disability, the implementation of policies is seldom attainable because of a lack of human, infrastructural and fiscal resources (Adnams, 2010).

Adnams (2010) also pointed to the following shortcomings within the South African public services that are accessed by persons who have ID:

- 1) Specialised mental health care services show spatial inequality with most of the services located in metropolitan areas and smaller cities. Services for persons who have ID tend to be insufficiently staffed without adequate multidisciplinary input;
- 2) Children who have severe or profound ID continue to be deprived of any form of education; and mainstream education is likewise unable to meet the basic educational requirements of learners who have mild ID. This is due to historically disparate resource distribution between different educational systems during the Apartheid era (Adnams, 2010);

3) South African courts often refer persons who have ID for forensic health assessment if they were victims of sexual or violent crimes. This is done in order to ascertain whether the person would be able to testify in court. The process is complicated by protracted trial procedures and a failure to adjust such procedures to adults with known information-processing or communication deficits (Adnams, 2010; Njenga, 2009; Pillay & Kritzinger, 2008).

Caregivers of persons who have ID would therefore often have to deal with caregiving demands that are linked with inadequate formal support from public health services (Adnams, 2010), social services (McKenzie, McConkey, & Adnams, 2014), legal services during court proceedings (Pillay, 2012; Pillay & Kritzinger, 2008) and educational resources (Adnams, 2010; Molteno, Molteno, Finchilescu, & Dawes, 2001).

1.2.6 Conclusion

As described, the findings of well-designed epidemiological studies in high-income countries have highlighted the role of social factors as aetiological and maintaining conditions of parental stress among mothers of children who have ID (e.g., Emerson & Llewellyn, 2008). It is conceivable that some of these findings would also apply to middle-income South Africa, a country with considerably less fiscal and infrastructural resources (e.g., World Bank, 2012).

1.3 The Psychological and Physical Well-Being of Parents of Children who have ID

1.3.1 Introduction

An expansive body of research has investigated parental stress among mothers of children who have ID (e.g., Cuskelly, 2006; Hassall et al., 2005; C. Hill & Rose, 2009; Kim et al., 2003; Seltzer, Floyd, Song, Greenberg, & Hong, 2011; Singer, 2006; Singer et al., 2007). A growing number of studies have also focused on positive and enriching caregiving experiences, family cohesiveness and a sense of parental accomplishment (Grant, Ramcharan, & Flynn, 2007; Jokinen & Brown, 2005; Lloyd & Hastings, 2009; Rapanaro, Bartu, & Lee, 2008).

Using Medline, Academic Search Premier and PsychInfo, a database search identified only one South African study that has explored the caregiving experiences of three South African families with a family member that had an intellectual disability. The study consists of three case studies. Qualitative analysis led to the following findings: Parents reported ongoing worry and stress about financial hardship and a pervasive lack of funding to provide caregiving; they also found it difficult to balance their caregiving responsibilities with other household tasks. Lastly, the children's behavioural difficulties were described as stressful and challenging (Sandy, Kgole, & Mavundla, 2013). Although the study's use of interpretative phenomenological analysis (IPA) generated rich information about three families, methodological limitations include the lack of qualitative strategies to enhance rigour, thereby casting doubt on the credibility of findings (Edwards, Dattilio, & Bromley, 2004; Sandy et al., 2013). Even though the authors recommended strategies aimed at explicitly informing public health policies, the use of case study research to inform organisational or governmental policies and service-design has

been rejected by at least one expert in case study research (McLeod, 2011; Sandy et al., 2013).

The remaining part of this section will describe applicable findings across a wide-spectrum of family research in the ID field.

1.3.2 Ageing parents and the accumulation of stressful caregiving

experiences: The role of developmental considerations

A number of studies have investigated the longitudinal course of caregiving among older and younger parents of adults who have ID across different indices of maternal physical and psychological well-being. A number of differences were found between older and younger parents:

First, parents who are approaching old age face their own developmental challenges that are different from those experienced by younger parents. For example, the possibility of acquiring chronic physical illness increases exponentially with age. Physical illness may in turn affect a parent's capacity to continue caregiving (Dillenburg & McKerr, 2010).

Whilst some studies have suggested that the burden of care decreases as children grow older, there is also evidence that ageing mothers of adults who have ID sometimes continue to experience a relative high objective and subjective burden of care (Heller, Hsieh, & Rowitz, 1997; Pruchno & Meeks, 2004). Ageing parents also tend to worry about what will happen to their children in the event of their death (Dillenburg & McKerr, 2010; Ha et al., 2008).

Second, many of the psychiatric disorders such as schizophrenia and bipolar mood disorder have an age of onset in late adolescence or young adulthood (APA, 2013).

The onset of psychiatric disorder could precipitate behavioural change that requires psychological adjustment in parent and child; behavioural problems may also have a negative impact on the parent-child relationship (Coetzee & Johns, 2016; Heller et al., 1997; Kim et al., 2003).

Faust and Scior (2008) conducted semi-structured interviews on 13 British mothers of young adults diagnosed with ID and mental illness. The study's findings suggest that a diagnosis of psychiatric disorder in late adolescence or young adulthood often re-ignited unresolved parental feelings of dejection and sadness. Many of these negative feelings were originally experienced and processed at the time the child was diagnosed with ID. Among the small group of participants, their children's diagnosis of mental illness constituted another unexpected turn of events that was not dissimilar to the time when their children were diagnosed with ID (Faust & Scior, 2008).

These results should be interpreted with caution because of the small number of participants. The authors also noted that the children of most participants presented with high levels of independence with regard to mobility and activities of daily living. The experiences of parents whose children had more pronounced support needs in completing different activities of daily living (ADL) were therefore not covered by the interviews (Faust & Scior, 2008).

Third, as with all young adults, persons who have ID enter a crucial developmental stage when they leave school to enter the open labour market or sheltered employment (Eisenhower & Blacher, 2006). The adjustment process may be particularly difficult in the local context because of the limited access that young

adults have to sheltered employment and job opportunities in general (Adnams, 2010; Coetzee & Johns, 2016).

Fourth, there is some evidence that negative parenting experiences may have an accumulative effect when caregiving is provided over the course of decades (Kim et al., 2003).

Last, there is evidence that the prevalence and incidence of behavioural difficulties, e.g., aggression or demanding behaviour, is higher among young adults than children who have ID (Oliver, Petty, Ruddick, & Bacarese-Hamilton, 2012).

1.3.3 The relationship between cognitive variables and parenting stress

An increasing number of studies have investigated the role of cognitive factors among distressed parents of children who have ID (Benzies, Trute, & Worthington, 2013; Hassall et al., 2005; C. Hill & Rose, 2009; Woodman & Hauser-Cram, 2013).

Hassall and his colleagues (2005) assessed 46 English mothers of children and adolescents who had ID. A comprehensive selection of psychometric tests was used to examine relationships between maternal perceptions, parental stress, the child's behavioural difficulties and the degree of family support available to the participants (Hassall et al., 2005). The study design was replicated by C. Hill and Rose (2009) on 44 mothers of adults who have ID. Both studies required participants to complete the Vineland Adaptive Behavior Scales, a short-form of the Parenting Stress Index, the Parenting Sense of Competence Scale, the Parental Locus of Control Scale, and the Family Support Scale. Both studies employed statistical analysis by using Pearson correlation coefficients and regression analysis (Hassall et al., 2005; C. Hill & Rose, 2009).

Consistent with other research (Benzies et al., 2013; Hastings & Brown, 2002; Roach, Orsmond, & Barratt, 1999), the two studies have found a positive relationship between higher measurements of parental competence and lower ratings of parental stress among mothers of children and adults who have ID (Hassall et al., 2005; C. Hill & Rose, 2009). The two studies have also found an inverse relationship between an internal locus of control and parental stress (Hassall et al., 2005; C. Hill & Rose, 2009). In one of the two studies, regression analysis showed a high degree of convergent validity between self-efficacy and locus of control: the former did not reach statistical significance when measured separately from parental locus of control (Hassall et al., 2005).

In the study that focused on parents of children who have ID, parental satisfaction showed a negative correlation with parental stress. Parents also reported higher levels of parental stress if their children displayed behavioural difficulties (Hassall et al., 2005). In the study that examined cognitive factors among mothers of adults who have ID, regression analysis placed parental satisfaction in an intermediate position between parenting stress and the child's levels of independence; parental satisfaction also served as an intermediary between parenting stress and maternal perceptions regarding the caregiving support they receive from relatives (C. Hill & Rose, 2009).

The main contribution of the two studies lies in the distinction between parental stress and its associated concepts, i.e., locus of control, perceptions regarding the caregiving support from relatives, parental satisfaction and parental sense of competence. The two studies therefore generated and refined knowledge about the associations between different cognitive concepts that are linked with parenting stress (Hassall et al., 2005; C. Hill & Rose, 2009).

The two studies shared the following methodological weaknesses: First, the sample size of both studies was not large enough to assess the potential role of demographic differences such as age and employment status among participants. Second, each participant only received one assessment. Future research should include repeated measurements of the same constructs at different intervals. Last, it is possible that other relatives or teachers might have provided different ratings on indices that measured the child's independent abilities and behavioural difficulties. Future research may consider the use of more than one caregiver to complete rating scales that are based on informant-opinion (Hassall et al., 2005; C. Hill & Rose, 2009).

Other studies have examined the role of parental attributions as causative factors of maternal depression and parental stress among parents of children who have ID and behavioural difficulties (Hastings, 2002; Woolfson & Grant, 2006; Woolfson et al., 2010).

Attribution theory posits that a person's beliefs about the causality of specific events or behaviours will dictate the person's expectations with regard to the future outcomes of similar events or behaviours across three categories (Weiner, 1985):

First, *locus* is construed as being either internal or external; second, *stability* is perceived as being on a range from variable to invariable. Last, *controllability* is conceptualised as representing either controllability or uncontrollability (Weiner, 1985; Wright, Basco, & Thase, 2006).

Two additional attribution scales were proposed: the first scale, *intentionality*, denotes purposeful behaviour to obtain a preferred outcome (Weiner, 1985). The second scale, *globality*, refers to the generalisation of specific events. Discrete

events are generalised to represent other domains of a person's life as well. The ensuing magnification of these events is conceptually linked with depression (Wright et al., 2006).

For example, a depressed person may generalise her interpersonal relationships at work as representing all her relationships, e.g., family life, children and friends. She would subsequently develop negative perceptions about her interpersonal relationships even though most of her conflict pertains specifically to the working environment.

Only a few studies have examined parental attributions of mothers and fathers whose children have ID, or other developmental disabilities (DD). One study focused on attributions of controllability as an intermediary between the child's developmental disability and behavioural difficulties (Woolfson et al., 2010). The sample included 20 mothers of children who had DD and 26 mothers whose children did not have DD. The Parent Attribution Test measured levels of parental controllability against the severity of the child's behaviour as measured by the Child Behaviour Checklist. It was found that parents of children who had DD tended to give higher frequency ratings for their children's behaviour if they held parental attributions of low controllability, i.e., that there was relatively little they could do to alter their children's behaviour (Woolfson et al., 2010).

The authors put forward the term “*parenting paradox*” to describe an attributional double bind that is required to manage children who display problem behaviours: parents may experience negative emotions when they develop attributions that children intentionally or deliberately display behavioural difficulties. Simultaneously, some form of control from the child is required if parents aim to replace undesirable

behaviours by socially acceptable ones (Woolfson et al., 2010). While the study explored an area of ID research that has been understudied, the small sample size limits the generalisability of findings (Woolfson et al., 2010).

Parents of children who have ID and behavioural difficulties tend to develop perceptions that their children have low levels of controllability over their behaviour because of internal causes such as medical or psychiatric problems (Hassall et al., 2005; Woolfson et al., 2010). In such instances, parents are likely to be less motivated to adopt behavioural support programmes (Reimers, Wacker, Derby, & Cooper, 1995, as cited in Hassall et al., 2005, p. 416).

A summary of findings from a selection of studies that investigated cognitive variables of mothers of children (including adults) who have ID are provided in Table 1:

Table 1

Summary of Studies that Examined Cognitive Variables of Parenting Stress Among Parents Whose Children Have ID

Study	Participants	Design	Findings	Study Design: Strengths and Limitations
Minnes et al., 2007	Participants were recruited from different services that catered for adults who have ID. 80 parents (71 mothers and 9 fathers) of adults with ID participated. (Age of participants = 50-88 years; average = 65.7 years; age of children = 17-59; average age = 35.7 years. 69% of the adult children presented with behavioural difficulties.	Interviews were conducted and the following psychometric tests were used: Vinelands Adaptive Behavior Scales; the General Health Questionnaire; The Interpersonal Support Evaluation List; A Checklist of Services and Support for Individuals with Intellectual Disability; The Family Stress and Coping Interview; and The Centre for Epidemiological Studies – Depression Scale. Alpha coefficients were used and the mean scores and reliability of each psychometric test was statistically produced. Hierarchical multiple regression analysis established mediating variables between depressive symptoms and other variables such as the child's behavioural problems.	First, parental appraisals with regard to growing older and the experience of stress mediated the relationship between parental health and depression. Second, parental perceptions and appraisals about stress were associated with depressive symptoms. Last, parental appraisals mediated the relationship between the child's behavioural difficulties and maternal depression.	<u>Strengths</u> Comprehensive statistical analysis led to the generation of scientific knowledge and refinement of existing theory w.r.t. relationships between parenting stress, maternal adaptation, and broader indices of maternal mental and physical health. <u>Limitations</u> The comparatively small sample size limited the generalisation of findings. The cross-sectional design of the study did not allow the researchers to assess the course of the identified constructs over time.
Lightsey & Sweeney, 2008	Recruited from disability websites, 64 American parents whose children have ID participated in the study (Sample = 90). 26 participants did not complete all the psychometric or biographic information and were not included in the results. (Age range of participants = 22 to 58; average = 42.08; SD = 7.24; Age of children = average age of 9.5 years).	The following psychometric tests were used: The Coping Inventory for Stressful Situations; The Generalised Efficacy Scale; The Family Environment Scales, Third Edition; The Perceived Stress Scale; The Meaning in Life Questionnaire; and The Family Satisfaction Scale. Biographical information was also collected. The statistical analysis employed Pearson coefficients and hierarchical regression. Bootstrapping was used to ascertain mediation effects.	Mothers with lower levels of stress used emotion-focused coping less frequently. They also reported higher levels of family satisfaction and - cohesion. These factors accounted for 31% of the variance in family satisfaction. Self-efficacy failed to show a statistically significant correlation with family satisfaction.	<u>Strengths</u> The use of a comprehensive psychometric battery of psychometric tests isolated numerous related concepts of parental stress and coping. <u>Limitations</u> The small sample size. The lack of representation from American minority groups. The authors also postulated that the use of the internet might have led to an overrepresentation

Benzies et al., 2013:

From a group of 296 family caregivers of children that had different forms of developmental, physical and psychiatric disability, 195 Canadian mothers completed a telephonic survey and interviews. (Average maternal age = 37.6 (SD = 6.5 years); average age of child = 7.9 years (SD = 4.8 years).

Telephonic interviews were conducted as part of a longitudinal study at T1 and T2. There was an interval of 1 year between T1 and T2. The following measurements were used: Brief Family Assessment Measure III; The Parenting Stress Index – Short Form; and the General Self-Efficacy Scale.

A hierarchical regression model collated self-efficacy scores from T1 on the family's adaptation measured at T2. Data were analysed by using the SPSS programme.

Family adaptation showed a moderately negative relationship with parenting stress. Overall, the levels of self-efficacy on T1 had predictive value of the family's ability to adjust as measured at T2.

After controlling for family adaptation, maternal age and stress levels at T1, maternal self-efficacy was independently correlated with family adaptation at T2.

of middle-class Americans.

Strengths:

The longitudinal design and repeated measurement of family self-efficacy allowed the authors to track family coping over the course of time. The study was able to investigate family adjustment against the expected developmental challenges of parents and children.

Limitations:

A longitudinal design that measures change over a period of one year may not be able to isolate and trace many of the caregiving challenges that had unfolded over the course of decades of caregiving.

The study's focus on maternal self-efficacy did not cover related aspects such as the use of different coping strategies, different sources of parental stress, and family resilience.

The study included different forms of disability, e.g., physical and developmental disability, which may represent different caregiving challenges. (Watermeyer, 2013). Future research should consider the separate analysis of family adjustment according to the different forms of disability.

The research that is presented in Table 1 does not represent an exhaustive list. As described later in this chapter, many aspects of coping could be seen as cognitive

variables while other aspects of coping go over and beyond maternal cognitions (e.g., Glidden et al., 2006; Kelso et al., 2005).

1.3.4. Maternal depressive symptoms

Research has found symptoms of depression among a significant minority of ageing family members of adults who have ID (Chou et al., 2010; Ha et al., 2008; Pruchno & Meeks, 2004; Seltzer et al., 2011; Singer, 2006; Totsika et al., 2011).

While the depressive symptoms of parents whose children have ID have often been directly linked with demanding caregiving responsibilities (e.g., Singer, 2006), the aetiological base of depression is also firmly embedded in a genetic predisposition to develop a mood disorder (A. Beck & Alford, 2009; Wright et al., 2006). Depression is also at times precipitated and perpetuated by an array of negative life events that are not necessarily associated with parenting (Hayes & Watson, 2013).

As described earlier, well-designed epidemiological studies and contemporary longitudinal family research in the ID field refuted the results from earlier research that constructed caregiving as an isolated causative agent that is directly responsible for maternal depression (e.g., Emerson et al., 2006). It was found that *most* families of children who have ID are not at an increased risk for developing adverse mental health outcomes once socio-economic position, maternal education and the child's behavioural difficulties were controlled (Eisenhower & Blacher, 2006; Emerson & Hatton, 2009; Emerson et al., 2006; Glidden, Bamberger, Turek, & Hill, 2010; Singer, 2006).

Singer's (2006) meta-analysis investigated depressive symptoms among mothers of children who had DD against those whose children did not have DD. Effect sizes

were used to obtain severity ratings of maternal depression across eighteen studies.

The meta-analysis included studies if they met the following criteria:

- The use of a control group of mothers whose children did not have DD.
- The use of psychometric tests with adequate validity and reliability to measure depression.

The following exclusion criteria were set for the meta-analysis:

- Samples that included mothers whose children had physical disability.
- Research that lacked an adequate sampling size to enable the employment of sound statistical methods.
- Research that was eventually considered as outliers because of infrequent effect sizes that skewed results.

Singer (2006) also allotted quality weightings to each study in the following manner:

- A rating of 0 was provided if relevant demographic information was absent; and a rating of 1 was given if the following information was included: salary levels, occupation, cultural background, whether the participant was married, and highest level of education.
- A rating of 1 was given to studies that used recognised measurements to establish the level of the child's DD.
- Depending on the presence of statistical methods to control demographic differences between the experimental and control groups, ratings of either 0 or 1 were given (Singer, 2006).
- Doctoral theses were allotted a rating of 0; peer reviewed articles received a rating of 1.
- Studies were assigned with a rating of 1 if psychometric tests were included to measure depression. Tests that incorporated measurements of mood under

the auspice of other psychological constructs such as parenting received a rating of 0.

Singer (2006) statistically assessed the heterogeneity of variance across the eighteen studies and found an insignificant Q_w statistical score. The eighteen studies were subsequently grouped into one large sample comprising 6 641 parents of children who had DD; and 26 438 parents of children who did not have DD. The results could be summarised as follows:

- Mothers of children who had DD were more likely to meet the minimum threshold criteria on depression inventories than mothers whose children did not have DD.
- When compared with mothers whose children did not have DD, depressive symptoms were on average 10% more prevalent among the parents of children who had DD. It was found that 29% of these parents presented with depressive symptoms (Singer, 2006).
- Importantly, the majority of participants whose children had DD did not have depression.
- When compared to parents of children who had DD, parents of adults who had DD obtained smaller effect sizes that implied less pronounced symptoms of depression (Singer, 2006).

The sophisticated use of inclusion and exclusion criteria with sound statistical methods to compare findings across the different studies should be regarded as the methodological strengths of Singer's (2006) meta-analysis. Because it covered different studies, each with its own methodological designs, Singer (2006) was unable to isolate specific aspects of the children's clinical profiles, e.g., the child's level of ID and co-morbid psychiatric or medical diagnoses. Singer (2006) therefore

recommended that smaller qualitative studies should explore the role of contextual factors among depressed mothers of children who have DD.

Another study has examined the prevalence of depression among American mothers of adults who were diagnosed with mild and moderate ID. The study formed part of a larger longitudinal study that comprised assessments at four different points and interviews with 71 ageing parents of adults who have ID. Besides other instruments that measured positive affect and burden of care, maternal responses on the Center for Epidemiological Studies – Depression Scale and Self-Report Depression Questionnaire were used to measure maternal depression. Bivariate correlations were used. It was found that 24-27% of mothers whose children had ID met the minimum criteria for depression (Esbensen, Seltzer, & Greenberg, 2006).

Among the group of parents whose children had ID, the authors found that mothers were more vulnerable to develop depression if their children were diagnosed with depression (Esbensen et al., 2006).

Although the study has provided a valuable contribution to a focus area within ID research that has received scant attention, i.e., maternal depression among mothers of adults who have ID *and* co-morbid psychiatric disorder, there are some methodological limitations to the study: The study focused on adults who had mild and moderate ID and results cannot be generalised to adults who have severe and profound ID. In addition, the results were solely based on psychometric assessment and comprehensive psychiatric interviews were not held to confirm the diagnostic labels from psychometric assessment or explore the role of contextual factors among the participants (Esbensen et al., 2006).

A larger and more recent study investigated depression among 350 Taiwanese mothers of adults who had ID (Chou et al., 2010). Regression analysis established a prevalence of 64% to 72% for depressive symptoms. Mothers were more vulnerable to develop depression if they reported inadequate formal support and low subjective ratings of physical well-being (Chou et al., 2010).

The relatively large sample size and use of a recognised psychometric instrument with good empirical properties (Center for Epidemiological Studies – Depression Scale) should be considered as relative strengths of the study. The authors cautioned against the generalisation of findings to fathers of adults who have ID; the study also focused on only one district in Taiwan. As a cross-sectional study without a control group, it will also be useful if future research examines the unfolding experiences of depressed mothers of adults who have ID over an extended period of time (Chou et al., 2010).

It is difficult to determine why the study reported higher prevalence rates of depression when compared with the other studies that were described. Of note, the authors made it explicit that most participants were older, from lower SEP and educational status. It is therefore possible that the district that was sampled represented a population with significant psychosocial stressors, which might have had an impact on the self-reporting of depressive symptoms and subjective burden among participants (Chou et al., 2010).

1.3.5 Maternal anger

Anger is an emotion that is closely linked with perceptions of hostility and aggressive behaviours (Spielberger, Jacobs, Russell, & Crane, 1983, as cited in Renk, Phares, & Epps, 1999). The literature has broadly differentiated between two forms of anger, i.e., state and trait anger (Arslan, 2010; Deffenbacher et al., 1996; Forgays, Forgays, & Spielberger, 1997; Sprague, Verona, Kalkhoff, & Kilmer, 2011; Quinn, Rollock, & Vrana, 2014).

Trait anger represents a dispositional variable of personality which has a pervasive, albeit fluctuating, presentation through the course of time. Conversely, state anger comprises a transient reaction to specific events (Quinn et al., 2014; Spielberger et al., 1983, as cited in Renk et al., 1999).

State anger manifests as physiological and affective reactions that are placed on a continuum ranging from mild levels of irritability and discomfort to severe emotional abreactions of extreme anger (Deffenbacher et al., 1996). Deffenbacher and his colleagues (1996) have also found that persons with high levels of trait anger tend to report episodes of state anger more frequently than those who had lower levels of dispositional anger. Persons with high ratings of dispositional anger were also inclined to react with more pronounced and intense emotional and physiological displays of anger during distressing situations (Deffenbacher et al., 1996).

The manifestation of anger differs according to the manner in which it is directed. Anger tends to remain unexpressed when it is directed inwards (Arslan, 2010). Outwardly-directed anger will often find expression through verbal or physical outbursts. The control of anger implies that a person attempts to calm down and

regulate her anger through the use of intentional strategies to lower arousal levels (Arslan, 2010).

The experience of anger may precipitate negative appraisals of stressful situations, which in turn may result in unsuccessful coping efforts and a concomitant escalation of negative emotions (Arslan, 2010; Dreman, 2003). Arslan (2010) has found a negative correlation between inward manifestations of anger and problem-focused coping.

When focusing on parental anger, research has found that parents may respond with anger when their children present with aggression. It is posited that the child's behavioural difficulties could be linked with a genetic predisposition to react with anger or aggression in stressful situations (DeBaryshe & Fryxell, 1998; Dreman, 2003; Peterson, Ewigman, & Vandiver, 1994; Renk et al., 1999).

1.3.6 Positive aspects of parenting when raising a child who has ID

Although the majority of ID family research has revolved around the negative consequences of caregiving among family members of persons who have ID, an increasing body of literature has described positive aspects of parenting when raising a child who has ID (Blacher et al., 2013; Grant et al., 2007; Griffith & Hastings, 2013; Hall, Neely-Barnes, Kraff, Krcek, & Roberts, 2012; Hastings & Taunt, 2002; Lloyd & Hastings, 2009; Perkins & Haley, 2010; Rowbotham, Cuskelly, & Carroll, 2011).

Positive psychology focuses on the different psychological traits, strengths and abilities that enable persons to remain in good psychological health notwithstanding adverse life events and continuous stressors (Antonovsky, 1979). Within the field of ID family research, Lloyd & Hastings (2009, p. 958) have described the potential

usefulness of positive psychology in its ability in “identifying resilience as opposed to risk”.

Resilience could be defined as an organism’s capacity to cope, adjust and even flourish in adverse circumstances (McCubbin, 2001). The concept of resilience has often been criticised in the past for being conceptually too broad; and its incorporation of terms such as self-efficacy and self-esteem has also led to conceptual overlap and confusion (McCubbin, 2001).

When considering the findings from different studies that have explored positive aspects of parenting among mothers and fathers of children who have ID, a number of positive parental outcomes have been reported when adult children continue to live at home:

First, in a recent meta-synthesis of qualitative research that focused on families of relatives who had ID and behavioural difficulties, participants from different studies reported a special bond which existed between them and their children (Griffiths & Hastings, 2013). Participants have insisted that their relationships with their children were not only characterised by hardship, but also love, joy and commitment. Across the different studies that were included in the review, participants reported that the love and commitment towards their relatives compelled them to seek and access formal intellectual disability services (Griffiths & Hastings, 2013).

Second, younger parents have also described their relationship with their children who have ID as giving them a revitalised sense of meaning and direction in their lives (Blacher et al., 2013; Hastings & Taunt, 2002).

Third, parents of adults who have ID have also reported increased levels of parental satisfaction once they had adjusted to the implicit requirements of extended caregiving (Ollson & Hwang, 2008; Rowbotham et al., 2011).

Fourth, it has also been posited that parents gain skills and enhanced efficacy from their caregiving roles. Parents have also indicated that they were able to generalise many of the skills they have acquired as part of their caregiving responsibilities to other areas of their lives (Griffiths & Hastings, 2013).

Last, it has also been found that ageing parents were appreciative of the support they received from their children with disability in assisting them with common domestic tasks (Cuskelly, 2006).

1.3.7 The physical well-being of mothers whose children have ID

1.3.7.1 Introduction

The life expectancy of persons who have ID has increased significantly in high-income countries following advances in medical science and the ongoing focus on social valorisation and improvements in quality of life (Heller et al., 2007; Patja, Mölsä, & Iivanainen, 2001; Yoong & Koritsas, 2012). It is estimated that people who have mild ID now live into their late sixties and early seventies in high-income countries such as Finland and the United States (Heller et al., 2007).

Heller et al. (2007) have contextualised the role of medical advances in the life expectancy of adults who have ID by referring to earlier studies that estimate an increased life expectancy of 15 years for men and 22 years for women.

In light of increased longevity among adults who have ID, it is conceivable that parents may be required to provide caregiving over a comparatively longer period of

time. Research has correspondingly investigated the physical well-being of ageing mothers who are primary caregivers of adults who have ID. Some of the findings from recent studies will now be discussed.

1.3.7.2 Difference in physical and psychological health status according to different stages of development: Parenting in mid-life and old age

Research has examined the physical health-status of ageing parents of adults who have ID by comparing this group of parents with ageing mothers and fathers of adults who do not have ID (Ha et al., 2008; Heller et al., 2007; Seltzer et al., 2011; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Seltzer et al., 1995).

There are two theories that could be used to explain anomalous results from the reported developmental differences of parents when midlife reports are compared with the results when parents were in their sixties. The *cumulative stress theory* posits that parents will be adversely affected by an accumulation or pile-up of stressful caregiving events across a long period of time, which will result in increased subjective burden (Hall et al., 2012; Heller et al., 1997).

Contrary to this view, the *adaptational model* postulates that parental stress will decrease progressively, given that caregiving "...becomes less stressful over time, because of increasing stability in routines, a reduction in behavioural problems, greater acceptance of the family member and greater reciprocity in caregiving with the child with disabilities . . ." (Townsend, Noelker, Deimling, & Bass, 1989, as cited in Heller et al., 1997, p. 408).

The results from two recent studies will shed light on the two conflicting theories. A recent study formed part of a longitudinal research project that randomly sampled 10 317 Americans in 1957 after they had completed their secondary education at

different schools in Wisconsin. From the original sample, Seltzer and her colleagues (2011) identified 220 parents of adults who had DD against a control group of 1 042 participants whose children did not have DD.

The study has investigated the psychological and physical well-being of mothers whose children had DD. Participants completed psychometric self-reports and surveys at two different intervals: 1992-1994 and 2004-2006. The last survey included questions that probed whether participants had children diagnosed with an intellectual or developmental disability. The researchers considered the 1992-1994 results from surveys and self-reports as representing parents at midlife; the surveys and self-reports were completed approximately 10 years later by the same group of parents when they were in their sixties.

Participants completed a demographic questionnaire that included indices of SEP, occupational history and highest level of education. Assessment included a battery of psychometric instruments and self-report measurements of physical health:

- Center for Epidemiological Studies – Depression Scale.
- Ryff 's Psychological Well-Being Measure.
- On a 5-point Likert scale, self-ratings of body mass index, bodily pains, heart problems, and problems with physical health.
- The Health-Related Quality of Life Questionnaire.

Regression analysis and ANCOVAS were employed to measure and compare outcomes between the groups; Cohen's effect sizes were also used to quantify the significance of difference (Seltzer et al., 2011).

The results confirmed the following:

- Ageing parents of adults who had DD (on average in their mid-sixties) presented with significantly higher prevalence rates of depressive symptoms when compared with parents whose children did not have DD.
- Ageing parents of adults who had DD presented with higher body mass index scores and reported more cardiac problems than the control group. The former group also subjectively reported a greater number of general health concerns and a reduced capacity to complete self-help tasks and activities of everyday living.
- Compared with ageing parents of adults without a disability, ageing parents of adults whose children had DD reported less social engagement opportunities with family and other acquaintances.

Seltzer and her colleagues (2001) found significantly less health and psychological variation between parents with and without children who had DD when they analysed results from the earlier measurement that dated back to the 1990s, i.e., when participants from the same longitudinal study were in their fifties: in midlife, parents of adults who had DD reported a higher body mass index and more heart problems than parents of adults without DD, but variance with reference to other indices of physical health and maternal symptoms of depression failed to reach statistical significance.

The findings of the abovementioned longitudinal study support the *cumulative stress theory* (Seltzer et al., 2011). Moreover, reports of significantly less health and psychological problems in midlife than old age among the same participants highlight the importance of conceptualising caregiving along developmental trajectories (Seltzer et al., 2001; Seltzer et al., 2011).

The longitudinal study has methodological weaknesses that should be considered: First, the study comprised a group of mostly White middle-class Americans and findings are not representative of the American population. Second, some of the participants or their children passed away between 1996 and 2004. It is conceivable that some of these parents might have been in poor physical health and their inevitable exclusion from the 2004-2006 assessment had a bearing on results. Last, even though the survey covered thirty-one questions to ascertain whether some of the participants' children had ID or DD, it is possible that some of the parents might have erroneously ascribed traits of ID in the profiles of their children (Seltzer et al., 2001).

The results of another recent study stand in stark contrast to the findings of Seltzer and her colleagues (Ha et al., 2008; Seltzer et al., 2011). From a population-based sample of 7 108 Americans, the study included 296 midlife and ageing parents of children who had DD or mental health problems and 1 393 midlife and ageing parents whose children did not have a disability.

All the participants of the original study completed a questionnaire that included questions about the disability status of their children. The study followed a cross-sectional design. The participants were of different age groups and the difference between the oldest and youngest participant was 50 years. The study eventually comprised three samples: parents of children who had DD; those whose children had other mental health problems such as depression and anxiety; and parents of children who did not have DD or mental health problems (Ha et al, 2008).

A survey was used to measure positive and negative affect as well as physical health complaints and general psychological well-being. Relevant to the current

discussion, questions about parental physical health included Likert-scale items about the subjective experience of bodily pain (head and back), muscle pain, urinary incontinence and problems that were associated with sleep. Results were analysed with the use of ANOVA and post-hoc t-tests.

The findings of Ha and her colleagues (2008) could be summarised as follows:

- Compared to parents of children without DD or mental ill health, parents of children with either mental health problems or DD reported elevations in negative affect, poorer psychological well-being, and a significantly greater number of physical health complaints.
- Against the results from midlife parents of children who had DD, ageing parents of adults who had DD reported significantly less negative affect and a more positive sense of emotional well-being. The course of different developmental disorders was linked with the psychological well-being of parents, e.g. attention-deficit hyperactivity disorder and ID. However, the number of participants was too small to allow comparisons between different clusters of disorder within the broader developmental disorder group of parents (Ha et al., 2008).
- The reports of physical health complaints between midlife and ageing parents of children who had developmental disorder failed to reach statistical significance (Ha et al., 2008).

The study's representative sample of minority groups in the United States and use of rigorous statistical methods should be considered as methodological strengths.

Methodological limitations include the use of a cross-sectional design that precluded the comparison of the same persons at different intervals of assessment (Ha et al.,

2008). As opposed to the longitudinal study by Seltzer and her colleagues (2011), this study could not trace the changes that had occurred within individuals over time (Ha et al., 2008).

The study clustered various developmental problems together under the umbrella of developmental disorder. Participating mothers of children who had attention-deficit hyperactivity disorder (ADHD), epilepsy, learning disorders, and cerebral palsy were included in the developmental disorder group with parents whose children had ID and Down syndrome. In fact, ADHD and learning disorders were the diagnoses given by almost half of the participating mothers who formed part of the DD (Ha et al., 2008).

Based on the foregoing discussion, I would like to interpret the conflicting results of the two studies as follows:

- The authors of both studies have emphasised the need for further research to confirm results and the findings should be interpreted with caution (Ha et al., 2008; Seltzer et al., 2011).
- Accordingly, both studies noted parents of adults who have different forms of DD, including ID, tend to report lower psychological well-being and more physical-health complaints (Ha et al., 2008; Seltzer et al., 2011)
- There is evidence to support the cumulative stress theory when considering the experiences of ageing mothers of adults who have ID (Seltzer et al., 2011). More research is required to provide stronger evidence that would allow greater validity and generalisability across different cultural groups and countries (Seltzer et al., 2011).

- The inclusion of adults who had ADHD and learning disorders in the cross-sectional study of Ha and her colleagues (2008) imply that almost half of the participating mothers in the developmental disorder group had children who did not have ID. While the study's findings support the adaptational model, I would argue that the broad conceptualisation of disability cannot be generalised to confidently represent mothers of adults who have ID. Compared with adults who carry diagnoses such as ADHD, adults who have ID will generally require more support (and caregiving assistance) in terms of activities of daily and supported or semi-independent living (APA, 2013).

1.3.7.3 Physical health and physiological responses to stressful caregiving demands

Insufficient cortisol production and altered daily variation between peak and trough cortisol levels point to the dysregulation of the hypothalamic-pituitary-adrenal axis (HPA-axis) (Barker et al., 2012; Hartley et al., 2012; Seltzer et al., 2009).

A small number of studies have shown that parents of children with Fragile X or other DDs and behavioural difficulties tended to have disrupted cortisol production patterns on the days following stressful caregiving events (Barker et al., 2012; Hartley et al., 2012; Seltzer et al., 2009).

The corticotrophin-releasing hormone (CRH) represents the first point of the hypothalamic-pituitary-adrenal axis (HPA-axis). CRH is emitted into the hypothalamic-hypophyseal portal system, which in turn carries CRH to the anterior pituitary. CRH triggers the discharge of adrenocorticotrophic hormone (ACTH) within the anterior pituitary (Silverthorn, 2014). ACTH will then work on the adrenal cortex to enable the synthesis and discharge of cortisol (Silverthorn, 2014).

Cortisol is an indispensable glucocorticoid that is either stimulated or suppressed in the adrenal glands. Cortisol tends to have higher emission rates in the morning while production dwindles in the evening. Importantly, more cortisol is produced when a person experiences high levels of stress. Stressful events activate cortisol production during which some metabolic processes are prioritised over less important ones (Hartley et al., 2012). For example, during acute periods of stress a person's appetite is often suppressed while vital organ functions in the kidneys, heart and brain are increased. Cortisol production is not the only hormonal response against stressful events: other neurohormones such as adrenalin are also activated. In turn, adrenalin interacts with glucagon to increase glucose concentrations in the bloodstream. Under severe stress, the synergistic action between glucagon, adrenalin and cortisol acts as a protective and energising mechanism to deal with acute stress (Silverthorn, 2014; Hartley et al., 2012).

After cortisol is synthesised, it is distributed from the adrenal cortex via the blood stream to the immune system, liver, muscles and adipose tissues. The distribution generally takes place through the protein corticosteroid-binding globulin (CBG) to intracellular receptors across these areas (Dee et al., 2014).

A negative feedback loop is created when the body signifies the overproduction of cortisol to the anterior pituitary and hypothalamus. This results in the reduced production of CRH and ACTH (Dee et al., 2014). High levels of cortisol could increase the production of glucose via the liver and compromise a person's immune system. The overproduction of cortisol could also result in increased protein catabolism and lipolysis. The over- or underproduction of cortisol could have an influence on memory, mood and a person's capacity to process new information (Dee et al., 2014; Seltzer et al., 2009).

In the context of caregiving, a failure to produce adequate levels of cortisol in the morning could result in feelings of tiredness and fatigue later on in the day. This may in turn have an adverse impact on parental capacity and the ability to cope with distressing caregiving events (Hartley et al., 2012).

A decreased production of cortisol in the morning was found among 76 mothers of adolescent and adult children who were diagnosed with Fragile X syndrome if they were exposed to their children's behavioural difficulties the previous day (Hartley et al., 2012). By obtaining saliva samples at four different times each day on four days, this study used repeated measurements of cortisol production. The child's behavioural difficulties were also formally assessed by means of a parent report rating scale. For a study that targets a specific population, a relatively large sample, in which demographics and SEP were controlled, added methodological strength. Two of the four saliva samples were obtained within an hour after the parent had woken up. This should be considered as a strength, as this minimised the possibility that stressful events on the same day could have had an impact on cortisol production. The lack of representation from American minorities was cited as one of the main weaknesses of the study. The study only focused on mothers with the premutation of Fragile X as established via the full mutation of their children. The study is therefore not representative of persons with the premutation without children, or mothers whose children did not have the full mutation (Hartley et al., 2012).

In another study, midlife mothers of adults who have ID showed greater levels of cortisol hypoactivation than mothers of non-disabled children when they spent more time with their children (Seltzer et al., 2009). Likewise, a third study found similar

trends of hypoactivation among mothers of adults who have psychiatric disorder after they had experienced greater levels of stress the day before (Barker et al., 2012).

1.3.7.4 The Dynamic Model of Affect: Possible links between parental health-stress, affect and appraisals

The Dynamic Model of Affect posits that perceptions of poor physical health could potentially reduce a person's ability to regulate their emotions during stressful life situations (Pruchno & Meeks, 2004). Moreover, health stress hinders a person's ability to discriminate positive from negative emotions when dealing with stressful environmental triggers (Pruchno & Meeks, 2004).

In less stressful situations, a person tends to separate positive from negative emotions when deciding on the best course of action to deal with the stressor. If stress escalates to a point where the stressor is considered as uncontrollable, individuals tend to collapse positive and negative affective states into a singular, abridged emotional reaction that has as its sole purpose the prevention of escalated uncertainty (Pruchno & Meeks, 2004).

Pruchno and Meeks (2004) measured health stress, positive affect, negative affect and depression among two groups of ageing parents of adults who have ID. The two groups comprised mothers who were highly stressed about their health (n = 485) and those who showed lower levels of stress about their general physical health (n = 447).

The authors postulated that the capacity of mothers to provide care would be negatively affected by prominent health-related stresses. High levels of health stress would be characterised by increased negative affect, lower reports of positive affect and increased depressive symptoms (Pruchno & Meeks, 2004).

The group of parents with high levels of health stress reported more symptoms of depression; they also described less positive and more negative affect when compared with the other group (Pruchno & Meeks, 2004). The findings suggest that mothers with high levels of health stress may be more vulnerable to develop depressive symptoms when faced with ongoing caregiving stressors (Blacher et al., 2005; Pruchno & Meeks, 2004).

1.3.7.5 Conclusion

Although not conclusive, there is an increasing body of evidence that has found elevated levels of parental stress and maternal depression among mothers of children and adults who have ID. As described in the previous chapter, socio-economic position, maternal education and other psychiatric diagnoses account for a considerable part of the variance in the association between parenthood and parental stress (e.g., Emerson et al., 2006).

1.4 The Behavioural Difficulties of the Child

1.4.1 Introduction

Research has linked different child variables with higher levels of parental stress, including the presence of mental illness in the child (e.g., Berg-Nielsen, Vikan, & Dahl, 2002; Brannan & Heflinger, 2001), behavioural problems (e.g., Farmer et al., 1997; McStay et al., 2014), causes of ID (e.g., Blacher & McIntyre, 2006), the severity of ID (e.g., Holden & Gitlesen, 2004), adaptive abilities (e.g., Haveman et al., 1997), social skills (T. B. Smith et al, 2001), SEP and hardship (e.g., Hatton & Emerson, 2009), and family characteristics (e.g., Frey, Greenberg, & Fewell, 1989).

Different terms such as behavioural difficulties and problem behaviours are used to refer to challenging behaviour (CB). CB refers to an umbrella term that represents

numerous forms of different behaviours (Deb, Thomas, & Bright, 2001). The terms *behavioural difficulties* and *problem behaviour/s* are used in the present study to refer to the different behaviours that reside under the rubric of *challenging behaviour*.

1.4.2 “Behaviour that challenges us” – the phenomenon of CB in services for people who have ID

Problem behaviour among persons who have ID has received extensive attention in research (McClintock, Hall, & Oliver, 2003). A generally accepted definition of problem behaviour considers risk to the self or others as preventing optimal access to community resources (Kushlick, Trower, & Dagnan, 1997).

Emerson's definition of CB is widely used in the field of ID research. Emerson (1995, as cited in Kushlick et al., 1997) defines challenging behaviour as:

behaviour of such an intensity, frequency and duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community resources. (p. 140)

The categorisation of different forms of CB remains a contentious issue in research for a number of reasons:

First, research has often been inconsistent in its classification of problem behaviours; and different criteria of discrete sets of behaviours have been employed across different studies (Cooper et al., 2009; McGillivray & McCabe, 2006).

Second, some of the studies that have investigated CB have included children and adults in the same sample. The findings from these studies were therefore not

sensitive to the role of developmental considerations across different age-groups (Myrbakk & Von Tetzchner, 2008).

Third, the employment of different methodological designs makes it difficult to replicate findings, especially when different data collection methods were used (Deb et al., 2001; Dilworth, Phillips, & Rose, 2011).

Fourth, earlier ID research has also been criticised for its lack of standardised criteria to define and operationalize different forms of problem behaviours (Joyce, Ditchfield, & Harris, 2001; Royal College of Psychiatrists, 2001). For example, some studies tended to only focus on severe self-injurious behaviour whereas others included milder forms of self-injury (Joyce et al., 2001).

Last, the interchangeable use of the concepts *problem behaviour* and *mental illness* or *psychiatric disorder* has also been criticised. The aetiology of problem behaviours will be described later in the chapter; and it will be evident that behavioural problems are not necessarily the result of psychiatric symptoms or conceptualised as atypical symptoms of psychiatric conditions (Allen, Lowe, Matthews, & Anness, 2012; Matson, Neal, & Kozlowski, 2012; McIntyre et al., 2002).

The lack of standardised criteria and operationalised descriptions of problem behaviours have made it difficult to establish its prevalence rate. The prevalence of CB has accordingly been estimated to range between 4% and 64% of persons who have ID (Allen et al., 2012; Deb et al., 2001). However, it is generally considered that problem behaviours are prevalent among 10-20% of individuals who have ID (De Winter et al., 2011; McClintock et al., 2003; Totsika et al., 2011).

In order to address the lack of consistency with regard to standard criteria and the operationalisation of different forms of problem behaviours, the Royal College of Psychiatrists (2001) has published a hierarchical diagnostic system, the Diagnostic Criteria for Psychiatric Disorders for use with Adults with Learning Disabilities/Mental Retardation (DC-LD). The DC-LD is based on expert opinion and provides diagnostic criteria for psychiatric disorder among adults who have ID. The DC-LD also describes different forms of problem behaviours (Royal College of Psychiatrists, 2001):

- Verbally aggressive behaviour.
- Physically aggressive behaviour.
- Destructive behaviour.
- Self-injurious behaviour.
- Sexually-inappropriate behaviour.
- Oppositional behaviour.
- Demanding behaviour.
- Wandering behaviour.
- Other problem behaviours such as non-epileptic seizures; psychogenic polydipsia, spitting, playing with food; deliberate urinary and faecal incontinence; soiling and or smearing; throwing objects; hoarding; stealing; begging; making hoax telephone calls; repeated lying; etc.

In order to assess whether the abovementioned problem behaviours require further clinical attention, the Royal College of Psychiatrists (2001, p. 83) has adopted diagnostic criteria to assess the frequency, severity and duration of different problem behaviours:

IIID 1.1 General diagnostic criteria for problem behaviours

- A) The problem behaviour is of significant frequency, severity or chronicity as to require clinical assessment and special interventions/support.
- B) The problem behaviour must not be a direct consequence of other psychiatric disorders (e.g., pervasive developmental disorders, non-affective psychotic disorder, depressive episode, generalised anxiety disorders, obsessive-compulsive disorder, personality disorders), drugs or physical disorders.
- C) One of the following must be present:
 - 1. The problem behaviour results in a significant negative impact on the person's quality of life or the quality of life of others. This may be owing to restriction of his or her lifestyle, social opportunities, independence, community integration, service access or choices, or adaptive functioning.
 - 2. The problem behaviour presents significant risks to the health and/or safety of the person and/or others.
- D) The problem behaviour is persistent and pervasive. It is present across a range of personal and social situations, although may be more severe in certain identified settings.

(Royal College of Psychiatrists, 2001, p. 83)

The diagnostic criteria of problem behaviours describe their negative impact on adults who have ID and their families. Problem behaviours are often associated with unsuccessful adjustment in community-based accommodation settings and family living (Joyce et al., 2001; Lee & Kiemle, 2014; McIntyre et al., 2002). There is also evidence of associations between burden of care, caregiver strain and the problem

behaviours of service users in services for persons who have ID (e.g., Allen & Davies, 2007; Mills & Rose, 2011). The person who displays problem behaviours might also be subjected to drastic intervention strategies (Robertson et al., 2005)

It should be noted that DC-LD criteria do not attempt to capture novel psychiatric diagnoses, but is based on a hierarchical system which implies that these behaviours are not better accounted for by other diagnostic considerations associated with information processing, medical and organic aetiological factors, and categorical aspects of different psychiatric diagnoses (Royal College of Psychiatrists, 2001). These diagnoses are ordered in multiple axes that are hierarchically constructed, i.e., clinical diagnoses on an axis should only be considered once it has been established that the symptoms are not better accounted for by the previous axis. The hierarchical approach is taken directly from the Royal College of Psychiatry's (2001) DC-LD and provided below:

Axis I: Level of learning disabilities

Axis II: Causes of learning disabilities

Axis III: Psychiatric disorders

Level A: Developmental disorders

Level B: Psychiatric illnesses

Level C: Personality disorders

Level D: Problem behaviours

Level E: Other disorders (p.13).

It is estimated that the prevalence of psychiatric disorder among people who have ID is 2 - 3 times higher than the general population (Bhaumik, Tyrer, McGrother, & Ganghadaran, 2008; Holden & Gitlesen, 2004; Kwok & Cheung, 2007; Royal College of Psychiatrists, 2001).

The hierarchical diagnostic system developed by the Royal College of Psychiatrists (2001) provides clarity about the structure that clinicians should use when conceptualising complex clinical conditions that include problem behaviour. If problem behaviour is accounted for by developmental disorder, a psychiatric condition or personality disorder, specifiers should be added that describe the form of problem behaviour according to the categories or forms of problem behaviours that were provided earlier in this section. The Royal College of Psychiatrists' (2001) criteria for problem behaviours that are secondary to different psychiatric problems are presented below:

IIID2.1(x-x) Problem behaviour/s due to pervasive developmental disorder
(type/s)

- A. The problem behaviour is of significant frequency or severity to require special interventions/support in addition to those for the pervasive developmental disorder.
- B. The problem behaviour/s is/are a direct consequence of pervasive developmental disorder.
- C. One of the following must be present:
 - 1. The problem behaviour results in a significant negative impact on the person's quality of life or the quality of life of others. This may be owing to

restriction of his lifestyle, social opportunities, independence, community integration, service access or choices, or adaptive functioning.

2. The problem behaviour presents significant risks to the health and/or safety of the person and/or others.

D. The problem behaviour is persistent and pervasive. It is present across a range of personal and social situations, although it may be more severe in certain identified settings (pp. 87-88).

IIID2.2(x-x) Problem behaviour/s due to psychiatric disorder

A. The problem behaviour is of significant frequency or severity to require special interventions/support in addition to those for the psychiatric illness.

B. The problem behaviour/s is/are a direct consequence of psychiatric illness.

C. One of the following must be present:

1. The problem behaviour results in a significant negative impact on the person's quality of life or the quality of life of others. This may be owing to restriction of his or her lifestyle, social opportunities, independence, community integration, service access or choices, or adaptive functioning.

2. The problem behaviour presents significant risks to the health and/or safety of the person and/or others.

D. The problem behaviour occurs during the course of the psychiatric illness. It is present across a range of personal and social situations, although it may be more severe in certain settings (pp. 88-89).

B.1) Aggressive behaviour among adults who have ID

The DC-LD criteria for aggression are provided below (Royal College of Psychiatrists, 2001):

IIID 1.2 Verbally aggressive behaviour

- A. General diagnostic criteria for problem behaviour are met.
- B. Verbal aggression must have occurred on at least three occasions in the preceding six-month period, for example the person uses his or her voice in a violent or threatening manner. This may be impulsive or planned, and must occur in the context of minimal or no provocation by others (p. 84).

IIID 1.3 Physically aggressive behaviour

- A. General diagnostic criteria for problem behaviour are met.
- B. Physical aggression must have occurred on at least three occasions in the preceding six-month period, for example the person uses or threatens physical violence. This may be impulsive or planned, and occurs in the context of minimal or no provocation by others. Severity may range from pushing, slapping, and physically intimidating, to punching, kicking, biting, pulling the hair of others and more serious physical assault (p. 84).

IIID 1.4 Destructive behaviour

A. General diagnostic criteria for problem behaviour are met.

B. Destructive behaviour must have occurred on at least three occasions in the preceding six-month period, for example the person damages property, such as tearing paper and fabrics, smashing furniture and glass, to more serious property damage and fire setting.

This may be impulsive or planned, and occurs in the context of minimal or no provocation by others (pp. 84-85).

Aggressive behaviour remains one of the most difficult forms of behavioural problems for families and ID services to manage (McDonnell, 2010). As such, aggression is among the most frequent forms of problem behaviour that is reported in community and residential ID services (Cooper et al., 2009; Felce et al., 2015; Lowe et al., 2007; McDonnell, 2010). Studies have highlighted the negative impact of aggression on a person's self-esteem, social relationships and overall quality of life (e.g., Lowe et al., 2007). It is also associated with a breakdown of community residential placement and employment (e.g., Cooper et al., 2009; Felce et al., 2015; Lowe et al., 2007); and aggression adversely affects families, including mothers and siblings (McIntyre et al., 2002). Aggression has also been directly implicated in forms of offending behaviour and personality disorder (e.g., Alexander et al., 2010; Lindsay et al., 2006; Tyrer, Oliver, & Tarabi, 2014).

Prevalence studies of aggression in the ID population have yielded highly varying results of between 2.1% to 51.7% (Cooper et al., 2009; Felce et al., 2015). Similar to the wide range of prevalence rates that have been reported in studies that have focused on problem behaviours, the varying prevalence rates of aggressive behaviour could be attributed to different methodological designs (Cooper et al., 2009).

Cooper and her colleagues (2009) have conducted a large longitudinal study that was based on a rigorous methodological design: all the adults who have ID within the Greater Glasgow Health Board area were asked to partake in the study and 65.5% agreed to participate. From a cohort of 1 023 adults, 651 persons took part in the study, and 100 participants met the DC-LD criteria for aggression. Aggression was measured at two intervals with a two-year period between the two assessments, although some of the measurements were also conducted between the two assessments. Besides the use of DC-LD criteria, the researchers had also used Steve Moss's Psychiatric Assessment Schedules for Adults with Developmental Disabilities (PAS-ADD) and the Vinelands Adaptive Behavior Scales (Cooper et al., 2009). χ^2 tests, t -tests and univariate regression were used to establish a prevalence of 9.8% for aggression among adults who have ID while the 2-year incidence was estimated to be 1.8%. The study had considerable strengths that included a high rate of retention between the two intervals of measurement, the use of a defined population area to recruit participants, and the use of DC-LD criteria to measure aggression. However, the authors stated that a cohort of just over a thousand participants was not large enough to comprehensively explore the incidence of aggression and isolation of aetiological patterns (Cooper et al., 2009).

Research has found that aggression is more prevalent among younger persons between 20 and 35 than older adults (Tyrer et al., 2006). Aggression also shows an inverse relationship with severity of ID, i.e., the prevalence of aggression is higher among people who have severe and profound ID (Crocker et al., 2006).

While most of the earlier studies have found that men more frequently engage in aggressive behaviour, the abovementioned study by Cooper and her colleagues (2009) has identified a higher prevalence rate of aggression among women.

Aggression has also been described as expressions of behavioural phenotypes, e.g., fetal-alcohol spectrum disorder (National Association for the Dually Diagnosed, 2007; Royal College of Psychiatrists, 2001).

The relationship between aggression and psychopathology remains inconclusive although pervasive developmental disorder and ADHD have consistently been linked with increased aggression (Cooper et al., 2009).

1.4.3 The treatment of problem behaviour

1.4.3.1 Introduction

An extensive discussion of the available psychotherapeutic, behavioural and pharmacological treatments for the management of behavioural difficulties goes beyond the scope of this study. A brief discussion is warranted because parental stress and the child's behavioural difficulties could potentially be mutually reinforcing (e.g., Hastings, 2002; McDonnell, 2010).

The management and treatment of aggressive behaviour and other forms of problem behaviour mainly reside under two broad categories: behavioural management and pharmacological treatment (Allen, 2000; Bhaumik, Gangadharan, Hiremath, & Russell, 2011; Deb & Unwin, 2007; Harvey, Boer, Meyer, & Evans, 2009; Matson et al., 2012; McGillivray & McCabe, 2006; Robertson et al., 2005; Romeo, Knapp, Tyrer, Crawford, & Oliver-Africano, 2009).

1.4.3.2 Pharmacological treatment

There is some evidence of the effectiveness of psychotropic medication to manage behavioural problems that are displayed by people who have ID (Bhaumik et al., 2011). Against this, the widespread use of antipsychotic medication and other neuroleptics to treat problem behaviour remains contentious for the following reasons:

First, the use of antipsychotics and other neuroleptic medication is not grounded in a comprehensive evidence-base. There are relatively few randomised controlled trials (RCTs) that have included the use of pharmacological treatment for problem behaviours among persons who have ID (Heyvaert, Maes, & Onghena, 2010; Scheifes, Stolker, Egberts, Nijman, & Heerdink, 2011).

In a recent meta-analysis, only fourteen of the twenty-seven RCTs have provided the selection criteria that were employed to validate the diagnosis of ID among participants. Many of these studies have used large samples; and the participants that were diagnosed with ID often represented only a small proportion of the larger sample that included persons who did not have ID (Scheifes et al., 2011).

The authors also concluded that a meaningful analysis and comparison between different studies were hampered by the diversity of participants who were diagnosed with ID. More specifically, many of the RCT studies included different age groups; different forms of problem behaviours also tended to be clustered together (Scheifes et al., 2011). The relative paucity of well-controlled studies has also been criticised in other literature reviews (e.g., Benson & Brooks, 2008; Heyvaert et al., 2010).

On a more promising note, a double blind randomised controlled trial has found evidence that confirms the efficacy of atypical antipsychotics in reducing aggression among persons who have ID (Robertson et al., 2005).

Second, the side-effects of pharmacological treatment may also have a negative impact on behavioural management programmes (Deb & Unwin, 2007; Matson et al., 2012). For example, sedation and concomitant problems with focus and concentration might lower a person's ability to participate in differential reinforcement schedules (Matson et al., 2012).

In addition, the high co-morbidity of other medical conditions among people who have ID requires a careful analysis to mitigate the risk of deleterious interactions between neuroleptics and prescribed medication for chronic diseases (Matson et al., 2012).

Last, there is conflicting evidence that problem behaviour is directly associated with psychiatric symptoms (Matson et al., 2012). The widespread proclivity of clinicians to equate problem behaviours to pathoplastic symptoms of existing psychiatric disorders goes against the findings of many studies. More specifically, there is growing evidence that problem behaviours are sometimes caused and maintained by independent ecological variables (Matson et al., 2012; Sturmey, Laud, Cooper, Matson, & Fodstad, 2010; Tenneij & Koot, 2008).

Associations between socio-environmental factors and problem behaviours do not contest the established links between problem behaviours and psychiatric disorders such as depression, schizophrenia and bipolar mood disorder (Allen & Davies, 2007; Felce, Kerr, & Hastings, 2009; Holden & Gitlesen, 2009; Hurley, 2008). Rather, problem behaviour is seen as a complex phenomenon that may be caused by

different combinations of biological and environmental factors; and at times environmental triggers are clearly evident (Matson et al., 2012).

However, problem behaviour could also be caused by atypical psychiatric symptoms or be the result of psychiatric symptoms (Allen & Davies, 2007; Holden & Gitlesen, 2009). For example, verbal aggression is described as an atypical symptom of depression (Royal College of Psychiatrists, 2001). Conversely, it could also be the result of heightened irritability, which represents another symptom of depression (Allen & Davies, 2007; Holden & Gitlesen, 2009; Royal College of Psychiatrists, 2001).

Problem behaviours may also co-exist with psychiatric disorders without being caused by psychiatric symptoms (Allen & Davies, 2007; Holden & Gitlesen, 2009; Matson et al., 2012; Royal College of Psychiatrists, 2001). The Royal College of Psychiatrists (2001) makes it explicit that problem behaviours lack psychiatric diagnostic value and functions merely as a descriptive account of behaviours that are socially unacceptable.

1.4.3.3 Psychological interventions

a) Behavioural interventions

While there is substantial evidence that lends credence to the efficacy of behavioural intervention in the form of differential reinforcement and the use of functional assessment to reduce or mitigate problem behaviour among people who have ID, the preponderance of behavioural research in this area mostly consisted of single case designs or small controlled and non-controlled ABA designs that were not randomised (Allen, 2000; Chowdhury & Benson, 2011; Harvey et al., 2009; Matson et al., 2012; Sturmey, 2005).

Positive programming has gained recognition as an important behavioural intervention that is widely applied to manage problem behaviour including aggression (Matson et al., 2012; Kushlick et al., 1997; McClean & Grey, 2012). Positive programming consists of a functional analysis and the employment of differential reinforcement that uses positive reinforcement and extinction to decelerate undesirable behaviours (McClean & Grey, 2012). The use of stimulus control and crises intervention strategies has also been successfully employed to mitigate the risk of acute behavioural outbursts (Kushlick et al., 1997).

b) Cognitive-behaviour therapy

Cognitive-behaviour therapy (CBT) is increasingly used to address problem behaviour among persons who have ID (Bhaumik et al., 2011; Jahoda, Dagnan, Stenfort Kroese, Pert, & Trower, 2009). A recent review has identified smaller studies that demonstrated the usefulness of CBT in the treatment of psychiatric disorders such as depression and anxiety (Bhaumik et al., 2011). The successful psychotherapy treatment of psychiatric conditions may also have a positive impact on the management of problem behaviour if there is a clear relationship between the two variables (Allen & Davies, 2007; Royal College of Psychiatrists, 2001).

As is the case with pharmacological treatment and behavioural intervention, there is a need for larger, randomised-controlled trials to establish the efficacy of CBT with people who have ID and problem behaviours (Bhaumik et al., 2011; Whitehouse, Tudway, Look, & Kroese, 2006; Willner, 2005). In this regard, two randomised control trials on anger management have provided promising evidence of the effectiveness of CBT among adults who have ID (Bhaumik et al., 2011; Taylor, Novaco, Gilmer, & Thorne, 2002; Willner, Jones, Tams, & Green, 2002).

c) Low-arousal approaches and the management of aggression

Low arousal approaches (LAA) are relevant to the current study because many of the theory's underlying tenets were incorporated into the therapeutic agendas of participating mothers. LAA describe non-aversive strategies to manage aggression among persons who have DD (McDonnell, 2010). LAA separate the management of aggression from its treatment: whereas treatment attempts to reduce the frequency, severity or duration of aggression, LAA attempt to manage the behaviour with the explicit goal of risk mitigation. Stated differently, LAA primarily attempt to ensure the safety of caregivers and the persons who display aggression regardless of whether such behaviours persist or not (McDonnell, 2010).

Aggression is conceptualised as the result from the reciprocal interaction between caregivers and persons who have ID (McDonnell, 2010). The emotional distress of caregivers could therefore have a direct impact on the escalation and maintenance of aggressive outbursts among persons who have ID. McDonnell (2010) accordingly recommends that caregivers should become aware of their own trigger points and agitation during crisis situations. LAA employ strategies to de-escalate such crisis situations in a non-invasive manner, including arrangements to set-up a low arousal environment. Parents and paid carers are also sensitised to the reciprocity of arousal between themselves and their child or service user (McDonnell, 2010).

d) Psychodynamic approaches when working with children and adults who have ID

Psychodynamic approaches in the disability field have provided valuable insight into the emotional lives of children and adults who have disability (Capri & Buckle, 2014; Sinason, 2010; Watermeyer, 2013; Watermeyer & Swartz, 2008). Psychoanalytic perspectives recognise that societal restrictions and unavailable or inadequate

utilitarian resources may have a disabling impact on a person, e.g., the absence of sign language interpreters in an organisation that renders services to people who are deaf (Sinason, 2010; Watermeyer, 2013). Psychodynamic literature also describes an internal, psychological response to disability and the disabling aspects of stigma, perceived difference and the social marginalisation of individuals who have disability (Sinason, 2010; Watermeyer, 2013).

Valerie Sinason (2010) has used the concept of secondary handicap to describe a person's reactions in dealing with a primary handicap or intellectual disability. Such reactions generally present in the form of defence mechanisms against unconscious anxiety or the emotional pain that is evoked by the primary handicap (Sinason, 2010).

The realisation of difference or “otherness” may also evoke feelings of emotional pain among persons who have disability (Watermeyer & Swartz, 2008, p. 601).

The painful realisation of your own limitations is not restricted to persons who have disability. As Sinason (2010) argues, adolescents and young adults have the developmental task of reconciling their unfolding ideals, dreams, aspirations and hope of the future with the limitations of their own intellect, talents and physical attractiveness:

Opening your eyes after adolescence to the realization that you will not be an Austen, Einstein, Madonna or Picasso can be painful enough to the ordinary adolescent. Opening your eyes to admitting you look, sound, walk, talk, move or think differently from the ordinary person, let alone a cult hero or heroine, takes greater reserves of courage, honesty and toleration of one's own envy (p. 18).

Persons who have ID may present with a mild secondary handicap that is characterised by efforts to lower their intelligence or communication abilities. Ironically, a person who has a mild secondary handicap often resorts to efforts of “exacerbating their original handicap to keep the outer world happy with them” (Sinason, 2010, p. 18).

Opportunist secondary handicap represents a more pronounced psychological reaction that is characterised by maladaptive personality development as a defence against the same painful knowledge of being different in a perceived adverse manner. Secondary handicap may also result from exposure to traumatic events in the person's life, and in such instances the secondary handicap acts as a defence against painful and traumatic memories of such events (Sinason, 2010).

Without negating the role of disabling external factors that perpetuate disability, psychoanalytic therapy construes many of the behavioural difficulties among persons who have ID as the result of their secondary handicap (Sinason, 2010). Therapists engage with persons who have ID in the containing space of the therapeutic relationship. Psychoanalytic therapists recognise that these individuals have emotional richness notwithstanding their intellectual impairment. Psychotherapy is therefore employed to lessen the impact of the secondary handicap in the person's life (Sinason, 2010).

In the context of the present study, it is important to note that the parents of children who have ID may also be affected by the same trauma that led to the formation of a secondary handicap in their offspring (Sinason, 2010).

1.5 Coping with Stressful Caregiving Demands

1.5.1 Introduction

The preponderance of research on parental stress has focused on coping models to examine parental appraisals and the coping resources and strategies that parents need to cope successfully with caregiving demands (e.g., Glidden et al., 2010; Glidden et al., 2006; Kelso et al., 2005; Kim et al., 2003; Mak & Ho, 2007; Paster, Brandwein, & Walsh, 2009; Seltzer et al., 1995; Woodman & Hauser-Cram, 2013).

Adverse caregiving events do not automatically result in parental distress and inadequate coping: research has also found that parents of children who have ID are generally resilient in managing stressful caregiving demands and everyday responsibilities (Emerson et al., 2006; Hastings, 2002; Seltzer et al., 2011).

In a recent meta-synthesis of qualitative research that has explored parental experiences and coping among mothers and fathers of persons who have ID and behavioural difficulties, participants from 17 different studies reported a special bond which existed between them and their children (Griffiths & Hastings, 2013). A literature review was conducted to identify studies that included the following qualitative strategies:

- The use of a qualitative research design, e.g., semi-structured or open-ended interviews and focus groups.
- Clear indications that recognised methods of qualitative analysis were employed, e.g., grounded theory.
- The inclusion of direct quotations and parental responses in the presentation of findings.

- The inclusion of parental feedback about their experiences when accessing ID services across different domains.
- Research that has focused on family experiences as opposed to paid carers.
- The behavioural profile of children who had ID had to include behavioural difficulties.

The authors used meta-ethnography to seek common thematic threads between the different studies. The following themes were identified across the selected studies:

First, family caregivers constantly referred to their love for family members who have disability as the driving force behind efforts to access equitable and responsive services for their loved ones. Their sense of commitment and love transcended the behavioural difficulties of the individual. Second, families reported the high caregiving demands and time-consuming requirements of care. The combination of persistent behavioural difficulties and time-constraints often led to decreased opportunities for family members to pursue social and recreational activities. Third, families reported high levels of distress when the behavioural difficulties of family members who had ID required a form of crisis intervention that included physical restraint. Fourth, families seldom drew distinction between behavioural support needs and other forms of formal support in education, vocational services and health support. There was an understanding that ID services had to be responsive and skilled to manage their family members' behavioural difficulties. Family members tended to report high levels of frustration with existing ID services because of the lack of respite opportunities. Many families also believed that services did not take their views and opinions into account. Conversely, families appreciated services that were responsive to the family's need and where the quality of intervention was

considered of an acceptable standard. Last, families were apprehensive and worried about the future, primarily because of concerns about the future caregiving of their relatives in the event that primary caregivers were unable to continue caregiving (Griffiths & Hastings, 2013).

The focus of the meta-synthesis on the caregiving experiences of family caregivers who have relatives with ID and behavioural difficulties has obvious relevance to the current study. As a relative strength of the review, its inclusion criteria were systematically applied to ensure that the selected qualitative studies incorporated recognised qualitative research designs and methods of data analysis. Yet the authors stated that findings should be interpreted with caution: The reviewers were unable to obtain adequate information about the demographic background of participants in some of the studies. The meta-analysis therefore has limited claims to generalisability because information about the SEP, employment status, family composition and health status of participants across different studies were not always available (Griffiths & Hastings, 2013).

1.5.2 The Folkman and Lazarus Process Model of Coping

The cognitive or process model of stress and coping has been widely used in ID family research to describe parental appraisals and the coping strategies that are employed to deal with distressing caregiving situations (e.g., Glidden et al., 2006; Glidden & Natcher, 2009; Kelso et al., 2005). The current study adopted Folkman and Lazarus's cognitive model of stress and coping and employed the Ways of Coping Questionnaire (WAYS) to explore the use of different maternal coping strategies among participating mothers. It is therefore important to provide a summary of the theoretical framework on which the theory was built.

The process model of coping deviates from earlier theories that have described stress as the physiological result of contextual stimuli (Folkman, 1984). Lazarus (1999) argued that cognitive appraisals and subsequent coping mediate the relationship between stressful environmental encounters and the adaptational responses that are used to attempt reductions in stress levels (Folkman & Lazarus, 1988; Lazarus, 1999).

The model places more emphasis on the process of coping than the outcome of coping efforts (Lazarus, 1999; Kelso et al., 2005). The subjective interpretation and appraisals of stressful situations affect coping responses in a fundamental manner (Kelso et al., 2005).

The model describes stress as the result of cognitive appraisals that evaluate available coping resources as inadequate or ineffective in dealing with the distressing situation (Folkman, 1984).

The Process Model of Coping posits that people develop primary and secondary appraisals about stressful life events (Folkman, 1984; Lazarus, 1999). Folkman (1984) distinguishes between three different types of primary appraisals: *harm/loss*, *threat* and *challenge*:

- *Harm/Loss* comprises appraisals of present events that are based on past experiences of loss.
- Appraisals of *threat* signify the possibility of the present event to *cause harm/loss*.
- *Challenges* are described by Folkman (1984, p. 840) as representing “an opportunity for growth, mastery or gain”.

For example, if a child displays verbal aggression towards his mother, based on previous episodes of similar behaviour the mother’s primary appraisal may be one of

harm. There may also be an element of threat if the child's verbal aggression is perceived as a precursor of physical aggression.

Secondary appraisals involve the assessment of available coping resources to deal with potential stressors (Folkman, 1984, Kelso et al., 2005). A person's coping resources could be divided into five categories:

- Problem-solving skills.
- Social networks (e.g., professional and informal social support, e.g., health care professionals and friends).
- "General and specific beliefs " (Kelso et al., 2005, p. 4). It includes beliefs regarding self-efficacy, controllability and meaning.
- Health, energy and morale.
- Utilitarian resources, e.g., financial resources (Schaefer, Coyne, & Lazarus, 1981, as cited in Folkman, 1984).

A person uses different coping strategies that are based on her available coping resources. Such strategies may be effective or ineffective; and coping does not imply a successful outcome but rather sustained engagement to *attempt* the resolution of stress (Folkman, 1984; Lazarus, 1999)

The process model of coping describes two main coping strategies: problem-focused coping and emotion-focused coping. Problem-focused coping refers to cognitive and behavioural strategies that attempt to change the stressor by directly reducing its negative impact on the person. Problem-focused coping attempts to solve the problems that are responsible for high levels of stress (Folkman & Lazarus, 1988).

Emotion-focused coping attempts to regulate and lessen the emotional impact of stressful situations, e.g., changing the meaning of an event without changing the reality of the relationship between the person and event (Folkman, 1984; Iwasaki, 2001; Lazarus, 1999). Emotion-focused coping is often considered as a successful strategy to reduce emotional distress in the short run. However, the use of emotion-focused coping could reduce the efficacy of coping over time, because the source of emotional distress is not directly addressed (Folkman & Lazarus, 1988; Lazarus, 1999).

Emotion-focused coping is also employed when a person perceives the stressful situation as uncontrollable. In the context of the current study, research has indicated that caregivers often perceive their children's mental illness as uncontrollable due to the relative unpredictability of psychiatric symptoms. Conversely, ID is seen as more predictable in its course. Parents also believe in general that ID lacks the episodic and sometimes prodromal fluctuations that are associated with mental illness (Kelso et al., 2005; Kenny & McGilloway, 2007; Kim et al., 2003).

1.5.3 Recent findings on available coping resources and strategies used by mothers of children who have ID

The use of problem-focused coping strategies has generally been described as more effective in reducing parental stress and depressive symptoms among mothers and fathers of children who have ID (Glidden & Natcher, 2009; Glidden et al., 2006; Kim et al., 2003).

As part of a larger longitudinal study, 97 married couples of children with suspected or clinically-confirmed DD participated in a study that explored the role of personality

traits and coping strategies in the psychological health of parents (Glidden et al., 2006). The study employed three psychometric tests, all with good validity and reliability scales: Folkman and Lazarus's Ways of Coping Questionnaire, the NEO Five-Factor Inventory and the Depression scale of the Questionnaire on Resources and Stress. Regression and multivariate analysis of variance were used to analyse data (Glidden et al., 2006).

The results suggest that parents more frequently employed problem-focused coping strategies than emotion-focused strategies, i.e., Planful Problem-Solving; Seeking Social Support and Confrontive Coping as opposed to Escape-Avoidance and Distancing. While Escape-Avoidance was less frequently used, this emotional-focused coping strategy was linked with lower levels of psychological well-being and increased reports of depressive symptoms. Parents also tended to employ Escape-Avoidance more frequently when they had obtained high ratings on the NEO Five Factor Inventory's Neuroticism and Extraversion scales, and low ratings on Conscientiousness (Glidden et al., 2006).

Neuroticism measures constructs such as anxiety, stress, anger, hostility, depression and impulsivity (Costa & McCrae, 1992). The use of sophisticated psychometric assessment and sound statistical analysis should be considered as relative strengths of the study, but the authors also stated that a longer trajectory of repeated measurements may be required to shed light on prolonged caregiving and its coping responses. This implies that future measurement will be required to track the following:

- Changes in the employment of different coping strategies to realign parental coping with changing developmental requirements in the lives of parents and their children.
- Longitudinal assessment will also shed light on the potential negative impact of the frequent use of Escape-Avoidance on the psychological well-being of parents (Glidden et al., 2006).

The use of a comparative group of parents whose children did not have DD would have allowed across-group comparisons, thereby strengthening the study.

Sixty-three of the participants who participated in Glidden and her colleagues' (2006) study were reassessed six years later (Glidden & Natcher, 2009). The following findings were reported:

- By and large, the coping strategies that were used by individual parents showed little variation over time: six years after completing the first assessment, parents continued to use similar coping strategies to the ones that were employed during the first assessment (Glidden & Natcher, 2009).
- In both articles, the use of Positive Reappraisal was linked with enhanced psychological well-being among participants (Glidden et al., 2006; Glidden & Natcher, 2009).
- Parents who scored high on the Neuroticism-scale of the NEO Five Factor Inventory more frequently employed Escape-Avoidance than parents who scored low on Neuroticism.
- The use of Escape-Avoidance at the first interval was positively correlated with reduced psychological well-being during the second interval of assessment (Glidden & Natcher, 2009).

One of the study's findings, i.e., that the increased use of emotion-focused coping was linked with symptoms of maternal depression, was replicated in other studies that have examined coping among parents of children who had DD (e.g., Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Kim et al., 2003; Seltzer et al., 2005; Paster et al., 2009; Taanila, Syrjälä, Kokkonen, & Järvelin, 2002; Woodman & Hauser-Cram, 2013).

With regard to specific forms of emotion-focused coping, *Distancing* implies that the significance of stressful encounters is reduced through intellectual efforts that facilitate a conscious disengagement from the situation. *Escape-Avoidance* constitutes cognitive and behavioural efforts to "*escape or avoid the problem*" (Folkman & Lazarus, 1988, p. 7)

Two earlier comparative studies have explored the use of emotional and problem-focused coping among ageing mothers of adults who have ID and mothers whose children had a mental health condition (Kim et al., 2003; Seltzer et al., 1995).

While the work by Seltzer and her colleagues (1995) made use of a cross-sectional design, the longitudinal study by Kim and her colleagues (2003) allowed the authors to follow changes in patterns of coping among 246 parents of adults who had ID and 74 mothers of adults who had a mental health condition. Self-report questionnaires were used at various intervals spanning over a three-year period. Similar to the findings of other studies (e.g., Glidden et al., 2006), on average the mothers of both groups did not significantly alter their coping strategies over the 36-month period. However, once the analysis focused on the research material of each participant on an individual level, the authors observed that approximately one third of the respondents significantly changed their coping strategies according to the changing

circumstances in their lives. Kim and her colleagues (2003) therefore concluded that coping could be highly dynamic on an individual level. Other findings included the following:

- Similar to the findings of Seltzer and her colleagues (1995), Kim and her colleagues (2003) found that parents of adults who had mental illness made more frequent use of emotion-focused coping than problem-focused coping. The authors postulated that parents had potentially little control over the distressing symptoms of psychiatric disorder and its associated neurobiological pathways. Problem-focused coping could therefore be hindered by limited parental control over their children's behaviour (Kim et al., 2003; Seltzer et al., 1995).
- In both studies, differences in the use of emotion- and problem-focused coping between the two groups of mothers disappeared after problem behaviours in their children who had ID were controlled (Kim et al., 2003; Seltzer et al., 1995).

The longitudinal design of the study conducted by Kim and her colleagues (2003) is an obvious methodological strength. However, the authors highlighted three methodological limitations to their sample: a small sample size of the group of mothers whose children had mental illness, the homogeneous nature of the sample, and the use of convenience sampling.

Seltzer and her colleagues used the Center for Epidemiological Studies – Depression Scale and the Multidimensional Coping Inventory in their cross-sectional study on 389 ageing mothers of adults who had ID, and 105 ageing mothers of adults who had mental illness (Seltzer et al., 1995).

Apart from the findings that were presented in the previous paragraphs, they also found that mothers of children who have ID had experienced greater depressive symptomatology when their children had co-existing behavioural problems. Among the other group of mothers whose children had mental illness, the presence of behavioural difficulties among their children was not a significant predictor of maternal depression. The authors have argued that behavioural outbursts were relatively predictable during acute episodes of psychiatric disorder. Against this, the presence of behavioural disorder among adults who have ID represented a more pronounced deviation from the caregiving challenges that are usually associated with adults who have ID. As Seltzer and her colleagues (1995, p. 73) put it: "It is possible, therefore, that parents of adults with disabilities find coping with demands that are inconsistent with their child's diagnosis to be more stressful than demands that are in line with their expectations of the disability". While the association between depressive symptoms and the presence of behavioural difficulties in the child's profile is especially informative, again, the study's methodological weaknesses, e.g., convenience sampling and the relatively small sample size of the group whose children had mental illness, limit the study's claims to generalisability (Seltzer et al., 1995).

The classification of different coping strategies as either emotion-focused or problem-focused has been criticised for a number of reasons:

First, people use a variety of emotion- and problem-focused coping strategies to deal with stressful events and seldom limit themselves to one of the two strategies (Lazarus & Folkman, 1988).

Second, it has been proposed that positive reappraisal should be categorised as a problem-focused strategy and not solely as an emotion-based way of coping (Seltzer et al., 1995; Woodman & Hauser-Cram, 2013).

Last, on a conceptual level it is often difficult to distinguish coping strategies from coping resources (Schwarzer & Schwarzer, 1996). Coping resources, the required internal and external sources that facilitate coping responses, are often also coping strategies, by which is meant the actions that are employed to deal with stressful situations (Folkman & Lazarus, 1988; Schwarzer & Schwarzer, 1996).

For example, during a stressful caregiving encounter, a child acts out and breaks a valuable vase. His mother copes by using positive reappraisal to ascribe new meaning to the event: it showed her that material possessions are fragile and transient; her relationship with her child is of much more value than getting upset over the loss of a (valued) object. As a result, she sells other valuable and fragile belongings, which reduces the risk of similar adverse incidents in future and has an immediate positive effect on the frequency of her child's destructive behaviour (accepting responsibility; problem-focused coping; but also the use of problem-solving as coping resource). Subsequently, her stress is attenuated by reductions in episodes of destructive behaviour, which has a positive bearing on her self-efficacy and parental satisfaction (coping resources).

Folkman and Lazarus (1988) have therefore recommended that research should move away from the problem and emotion-focused categories by measuring the different coping strategies and resources that are employed, often simultaneously, to deal with distressing events (Folkman & Lazarus, 1988; Woodman & Hauser-Cram, 2013).

By using the Multidimensional Coping Inventory on 92 mothers of adolescents who had ID, a recent T-2 prospective study sub-divided emotion- and problem-focused coping into eight categories (Woodman & Hauser-Cram, 2013). It was found that the use of Denial, Active Coping/Planning and Positive Interpretation, which correlates with positive reappraisal, lessened the impact of the child's behavioural difficulties on symptoms of depression among the participating mothers (Woodman & Hauser-Cram, 2013). The less frequent use of behavioural and mental disengagement was also positively correlated with lower levels of depressive symptoms.

Results have confirmed earlier findings that suggest that parents use an array of emotion-based and problem-focused coping to deal with distressing caregiving situations (e.g., Glidden et al., 2006; Kelso et al., 2005).

In the context of the present study, which used the Ways of Coping Questionnaire as opposed to the Multidimensional Coping Inventory that was employed in Woodman and Hauser-Cram's (2013) study, positive reappraisal corresponds to positive interpretations, which refer to "reframing a problem in a positive light or restructuring a stressful transaction in positive terms" (Woodman & Hauser-Cram, 2013, pp. 525-526). In Active Coping/Planning, Active Coping could be defined as "direct action to remove a stressor or lessen its effects" (Woodman & Hauser-Cram, 2013, p. 519.)

The negative impact following the use of behavioural and mental disengagement confirmed earlier findings (Seltzer et al., 1995). The findings of Woodman & Hauser-Cram (2013) have also corresponded with other studies that have linked escape-avoidance behaviour with increased maternal depression in mothers of children who have ID (Glidden et al., 2006; Paster et al., 2009) and autism (Dunn et al., 2001).

Escape-avoidance behaviour represents a domain on the Ways of Coping

Questionnaire, and refers to cognitive and behavioural efforts to avoid specific stressors (Folkman & Lazarus, 1988). Apart from its association with depression, Mental/Behavioural Disengagement also showed an inverse relationship with self-efficacy (Woodman & Hauser-Cram, 2013).

In contrast to the findings of other studies, Denial, or efforts to behave in a manner that deny the existence of the relevant stressor, acted as a protection against depression and also facilitated increased parental self-efficacy (Woodman & Hauser-Cram, 2013).

As an emotion-focused coping strategy, Woodman and Hauser-Cram (2013) have postulated that denial may limit the negative emotional impact of stressful events when the (perceived) uncontrollability of such events hinders access to other coping strategies, e.g., problem-solving. The protective function of denial also attests to the usefulness of a multidimensional approach to delineate individual measures of coping: if emotion-based coping strategies were measured without conceptual distinction and sub-categorisation, the suggested protective role of denial would most likely have been hidden by the sum of all the other constituents of the construct (e.g., Kim et al., 2003).

1.5.4 Parental reports on the use of formal and informal support as coping strategies

Parents of children who have ID described the benefits of a cohesive family system and access to a wider support network that consists of relatives and friends (Chadwick et al., 2013; Griffith & Hastings, 2013; Kelso et al., 2005; Kenny & McGilloway, 2007; Paster et al., 2009; Taanila et al., 2002).

Across different studies, mothers of adults who have ID presented with lower levels of parenting stress and depressive symptoms when they were actively supported by other children, relatives and friends (Chou et al., 2010; Heller et al., 1997; C. Hill & Rose, 2009).

Whereas these studies have investigated the positive role of informal support, other studies have also examined parental perceptions about the available formal support from health care professionals and services for people who have ID (Kelso et al., 2005; Kenny & McGilloway, 2007; McConkey, 2005; McGill, Papchristoforou, & Cooper, 2006; Power, 2008; Thackeray & Eatough, 2014).

Parents have generally valued professional support in the form of specific parental training initiatives and the ability to adjust service delivery according to the family's individual needs, especially in times of change (Chadwick et al., 2013; Griffiths & Hastings, 2013).

Conversely, parents have also criticised organisations that render services to people who have ID (Chadwick et al., 2013; Griffiths & Hastings, 2013; Kelso et al., 2005; McGill et al., 2006; Thackeray & Eatough, 2014). In some studies, different services for persons who have ID have been depicted as uncoordinated and not adequately integrated (Kelso et al., 2005; Wodehouse & McGill, 2009); parents have also

criticised the low levels of skills and knowledge of some of the professionals who work within ID services (Griffiths & Hastings, 2013). In addition, studies have reported that parents voiced concern about the accessibility of ID services by ethnic minorities in the UK (Hatton et al., 2010). Likewise, Irish parents have criticised the relative inaccessibility of some of the Northern Irish services for people who have ID (McConkey, 2005).

In a study which has reviewed the satisfaction of 66 parents about the quality of service they received from different ID organisations, less than a third of parents found psychological intervention or medical treatment of problem behaviour helpful. Compared with the negative feedback for psychological and psychiatric services, it is interesting to note that over half of the parents described how their children had benefited from communication training (McGill et al., 2006).

1.6 The Use of Cognitive-Behavioural Therapy with Parents of Children who have Intellectual Disability

The effectiveness of CBT has been demonstrated in many well-designed controlled studies (J. S. Beck, 1995). The efficacy of CBT to reduce symptoms of different psychiatric disorders have been established in meta-analyses and literature reviews including anxiety (e.g., Simos & Hofmann, 2013), unipolar depression (e.g., Kuyken, Dagleish, & Holden, 2007), and eating disorders such as bulimia and anorexia nervosa (e.g., Bulik, Berkman, Brownley, Sedway, & Lohr, 2007; Shapiro et al., 2007). CBT has also been used effectively to augment the pharmacological treatment of severe and persistent psychiatric disorders such as schizophrenia (e.g., Marcinko & Read, 2004) and bipolar mood disorder (e.g., Miklowitz & Scott, 2009). More than 300 RCTs have placed CBT as the most empirically-validated

psychotherapy (Hoffman, Asnaani, Vonk, Sawyer, & Fang, 2012; Wright et al., 2006).

Findings from a recent review have suggested that CBT significantly reduced symptoms of anxiety in adults who were older than fifty-five (Gould, Coulson & Howard, 2012). It should be noted that the combined effect size of the studies that were included in the review was smaller than other reviews that focused on the use of CBT with younger adults who presented with anxiety (Gould et al., 2012).

In light of the current study's focus on the caregiving experiences of older mothers who have children with ID and aggression, it is useful to briefly examine a small selection of studies that employed CBT with family members of persons who had cognitive or developmental disability.

CBT has been a therapeutic vehicle to address depressive symptoms among caregivers of family members who had dementia. A randomised CBT group intervention effectively reduced dysfunctional thoughts and alleviated symptoms of depression that were directly linked with adverse caregiving experiences (Márquez-González, Losada, Izal, Pérez-Rojo, & Montorio, 2007). Another study has used CBT on caregivers of people who were diagnosed with dementia (López & Crespo, 2008). Again, it was reported that CBT had facilitated changes in caregiving appraisals and the more effective utilisation of coping resources to enhance the emotional well-being of the family members who had provided care (López & Crespo, 2008).

As illustrated in Table 2, a practitioner review by Hastings and Beck (2004) identified six group intervention studies that used CBT to alleviate parenting stress among parents of children who had ID.

Table 2: *CBT and Parental Stress*

Study	Study design	Psychotherapy or counselling and assessment	Outcome and appraisal of methodological limitations
Gammon & Rose, 1991	Mothers randomly assigned to treatment (n=24) and non-treatment (n=18).	4-8 mothers meeting for 2-hour session once a week for 10 weeks. Focus on cognitive restructuring, problem solving, goal setting and social skills.	<p><u>Outcome:</u> Treatment group: Reduced parenting stress, improved problem solving and social skills.</p> <p><u>Strengths:</u> Inclusion of control group and the randomisation.</p> <p><u>Limitations:</u> Relatively small sample size limits generalisation of results.</p>
Greaves, 1997	<p>Mothers of children with Down syndrome were assigned to one of the following:</p> <ul style="list-style-type: none"> - Rational Emotive Therapy (n=21). - Applied Behaviour Analysis (n=17). - Non-treatment (n=16) group. <p>Tests used (selection of items from):</p> <ul style="list-style-type: none"> - Parental Dissatisfaction Scale. - Parenting Stress Index - Profile of Mood States - Eight State Questionnaire - Multiple Affect Adjective Checklist (Greaves, 1997). 	Rational Emotive Therapy (RET): 8 sessions once a week. Focus on disputing irrational beliefs and cognitive restructuring. Behavioural focus on enhancing parenting skills.	<p><u>Outcome:</u> RET reported statistically significant reductions in parenting stress, depression and increased parental satisfaction while no changes were reported in ABA and no-treatment groups.</p> <p><u>Strengths:</u> Randomisation of groups; inclusion of alternative intervention (ABA) and control group.</p> <p><u>Limitations:</u> Lack of follow-up post-assessment prevents interpretation of longer term outcomes (Greaves, 1997).</p> <p>Relatively small sample sizes.</p> <p>The inclusion criteria of having children who have Down syndrome are not a limitation, but it limits the generalisation of results to children who have ID and different genetic, psychiatric or behavioural profiles.</p>
Kirkham & Schilling, 1990; Kirkham, 1993	<p>Mothers of children who had DD assigned to a Life Skills Training group (n=143) or Parent Support group (n=72).</p> <p>Follow-up over 2 years: (N = 49 - Life Skills Training group; N = 27 - Parental Support group).</p> <p>Use of regression analysis to measure therapeutic change.</p>	Groups of 10-12 mothers: CBT related life skills training focusing on coping, problem solving, decision-making and social support. Support group: Focus on group discussions, guest speakers and bibliotherapy.	<p><u>Outcome:</u> Mothers in Life Skills group had reduced depression and stress as well as improved social support after participation in groups. Two-year follow-up likewise indicated lower depression and increased social support.</p> <p><u>Strengths:</u> Longitudinal design allowed measurement of depression and parental stress over the course of time.</p> <p>Use of rigorous statistical analysis with randomisation and a relatively large sample at the onset of the study.</p> <p><u>Limitations:</u> Significantly fewer participants took part in follow-up, thereby limiting generalisation of follow-up outcome measures.</p>
Nixon & Singer, 1993	<p>Mothers of children who had ID assigned to CBT group (n=18) and waiting list group (n=16)</p> <p>Use of co-variance analysis and effect sizes to measure therapeutic change.</p>	Five group sessions. Focus on cognitive distortions that contributed to self-blame and guilt. Cognitive restructuring of distortive beliefs.	<p><u>Outcome:</u> Statistically significant reductions with small to medium effect sizes in maternal guilt, negative automatic thoughts and depression among mothers who were assigned in the CBT treatment group.</p> <p><u>Strengths</u></p>

			<p>Use of effect sizes to measure the degree of therapeutic change.</p> <p><u>Limitations:</u> The lack of follow-up post-assessment.</p> <p>Small sample size.</p>
Singer, Irvin, & Hawkins, 1988	<p>36 parents of children who had ID were randomly assigned to intervention group (n=18) or waiting-list group (n=18).</p> <p>Covariance analysis was used measure therapeutic change.</p>	<p>8-10 parents attended weekly 2-hour group intervention for 8 weeks. Focus on self-monitoring and physiological reactions to stress, relaxation techniques, identifying cognitive distortions and cognitive restructuring.</p>	<p><u>Outcome:</u> Statistically significant reductions in state anxiety, trait anxiety and depression.</p> <p><u>Strengths:</u> Inclusion of mothers and fathers in study.</p> <p>Covered a range of CBT-related methods.</p> <p><u>Limitations</u> Small sample size.</p> <p>Did not distinguish mothers from fathers when statistical analysis was employed.</p>
Singer, Irvin, Irvine, & Cooley, 1989	<p>Parents of children who had ID randomly assigned to Intensive Support (n=28) and Less Intensive Support (n=21) groups.</p>	<p>Less Intensive Support groups received respite and case management services. More Intensive Support groups received CBT group intervention plus parent training in behavioural management – 2-hour weekly sessions over 16 weeks.</p>	<p><u>Outcome:</u> Clinically significant reduction in anxiety and depression was found in 50% of Intensive Support group as compared with less than 10% of less Intensive Support group.</p> <p><u>Strengths</u> One-year follow-up assessment to establish whether therapeutic gain was maintained.</p> <p>The separate statistical analysis of mothers and fathers could be considered as a methodological strength, albeit as part of a relatively small sample size.</p>

Note. Adapted from "Practitioner Review: Stress Intervention for Parents of Children with Intellectual Disabilities," by R. P. Hastings and A. Beck, 2004, *Journal of Child Psychology and Psychiatry*, 45, pp. 1342-1343. Copyright 2004 by Wiley Publishers. Adapted with permission.

The practitioner review highlighted a number of points:

First, with the exception of the study by Kirkham and Schilling (1990), most of the studies that were identified by Hastings and Beck (2004) consisted of small sample sizes of American mothers and fathers. The generalisation of findings is therefore hampered by these factors.

Second, CBT was at times combined with other interventions such as supportive therapy and parental skills training. While the latter firmly resides under behavioural interventions (Spiegler & Guevremont, 2003), future research should focus on the implementation of well-designed CBT programmes that clearly denote the methods that were used to allow the replication of similar methods by other researchers.

Last, all the studies that were included in the literature review focused primarily on outcome, i.e., whether the intervention in question led to statistically significant change. Future research should also qualify aspects of psychotherapy process, i.e., descriptive and interpretive research that would elicit the contextual factors among therapists and participants that led to therapeutic change.

In a subsequent meta-analysis, Singer et al. (2007) compared the efficacy of different components of behavioural group programmes for parents of children who had cognitive disability. Whereas Hastings and Beck (2004) identified group intervention studies that had employed cognitive-behaviour therapy or rational-emotive behaviour therapy (REBT), Singer and his colleagues (2007) formulated effect sizes to compare the efficacy of intervention studies that were demarcated into four distinct categories: *multicomponent training (MCT)*, *behavioural parent training (BPT)*, family research or *family systems intervention (FSI)*, and *cognitive-behaviour*

therapy (CBT) that included coping skills training. Following the identification of methodological shortcomings, one FSI study was not analysed (Singer et al., 2007).

MCT studies represented a combination of BPT and either CBT, FSI or other supportive interventions. BPT studies focused on parent training and initiatives to enhance communication between parent and child. BPT studies also used systematic input to reduce problem behaviour to facilitate a concomitant lowering of parental stress and depressive symptoms that were conceptually linked with the child's difficult-to-manage behaviour. CBT and FSI group intervention programmes were based on the core principles of CBT and family systems theory respectively (Singer et al., 2007).

The results of the meta-analysis that were conducted by Singer and his colleagues (2007) will now be discussed according to the categories in which the studies were subdivided. A total of 17 studies were identified in the meta-analysis; and the relevance of findings to the current study will also be considered.

The meta-analysis has found that BPT programmes were primarily focused on the reduction of the child's behavioural difficulties. BPT studies only yielded a small effect size as an indirect intervention to reduce parental stress (Singer et al., 2007).

In addition to BPT studies, the meta-analysis has also identified six studies that have employed CBT (Singer et al., 2007). The meta-analysis produced a small aggregate effect size that suggests that CBT was moderately but consistently effective as an intervention study that attempted to reduce parental stress (as opposed to BPT that reduced the child's behavioural problems) (Singer et al., 2007).

Results from the meta-analysis also suggest that multicomponent training, i.e., combinations of CBT and parental training initiatives, were more efficacious in reducing maternal depression and parental stress than standalone CBT or BPT intervention (Singer et al., 2007).

The five MCT intervention studies have a combined effect size of 0.90, which is significantly larger than the small effect sizes observed in the other two categories (Singer et al., 2007). A short description of the five MCT training studies that were included in the meta-review by Singer and his colleagues (2007) follows below. It should be noted that these studies all involved families of children who were diagnosed with DD.

Bristol and her colleagues applied a manualised programme, the Counseling and Treatment and Education of Autistic and related Communication-Handicapped Children (TEACCH), to treat depressive symptoms in an intervention group (n=14) and a control group (n=14) of parents whose children had autism. While pre-assessment yielded a small effect size ($d = 0.30$), a significantly larger effect size of 0.77 was obtained at follow-up. Intervention included aspects of stimulus and antecedent control; strategies to manage autism-related problem-behaviour; and individual support to parents. The number of hours of intervention was not disclosed (Bristol, Gallagher, & Holt, 1993, as cited in Singer et al., 2007).

The second MCT study that was identified by Singer and his colleagues (2007), an intervention study by Hudson and his colleagues (2003), will be discussed in more detail in the next section. The next section deals with psychological intervention studies with parents whose children had DD and behavioural difficulties.

The third MCT study cited by Singer et al. (2007) consisted of a behavioural support programme for parents of children who had autism. The intervention group consisted of 12 participants. The control group of five participants received no intervention (Salt, Shemilt, & Sellars, 2002, as cited in Singer et al., 2007). The programme included the following:

- Understanding cues from the child.
- Understanding the functionality behind behaviour as an interactional tool.
- "Introduce adult lead activities with time".
- "Maintaining balance between intrusion and distress".
- "Use imitation to access the child's world".
- "Use language contingent activities".
- "Use pauses effectively".
- "Introduce flexibility" (Singer et al., 2007, p. 365).

Apart from the abovementioned steps to assist in the management of the children's behaviour, parents also attended support groups (Singer et al., 2007). The intervention involved intensive psychological input: parents received eight hours of intervention every second week over the course of eleven months. Results confirmed significantly lower levels of parental stress among the parents who participated in the programme; and the study yielded a large effect size of 1.97 (Singer et al., 2007). However, considerable methodological limitations included the small sample size and lack of follow-up assessment.

In an older study, Singer and his colleagues facilitated parental group training that combined cognitive-therapeutic initiatives that attempted to reduce parental stress

with behavioural rehearsal exercises that focused on challenging caregiving situations. Thirty-six participants were equally divided into an intervention group and a control group. Behavioural techniques included progressive muscle relaxation, self-monitoring and cognitive restructuring (Singer, Irvin, & Irvine, 1989, as cited in Singer et al., 2007). One of the study's strengths related to the separation of mothers ($d = 0.72$) and fathers ($d = 0.45$) during the statistical analysis of results. Follow-up assessment was not conducted (Singer et al., 2007).

The other MCT training programme included parental training and psychoeducation, behavioural management, functional communication training, information about the organisations and services that were at the time offered to children who had autism, and familial and public perceptions with regard to autism. Information was also provided on how to deal with caregiving stress and psychological problems among parents of younger children who had autism (Singer et al., 2007; Tonge et al., 2006). The study design consisted of a randomised controlled trial in which 70 participants were divided equally into two groups: one group received psychoeducation and professional support to formulate a behavioural management programme; the other group received counselling. The General Health Questionnaire was used before intervention, after intervention was completed, and at follow-up. Effect sizes were relatively small after intervention was completed: the group who received behavioural management support and psychoeducation obtained an effect size of 0.31 post-intervention and 0.43 at follow-up (Singer et al., 2007; Tonge et al., 2006).

In the abovementioned study, it should be noted that both groups reported statistically significant improvement of mental health problems. In the behavioural management and psychoeducation group, results suggest that participants

experienced significant reductions in anxiety, sleep problems, bodily complaints and communication difficulties between family members. The improvement across the abovementioned domains was significantly higher than the group that received counselling (Tonge et al., 2006).

Of the 17 studies that Singer and his colleagues included in the meta-review, only seven studies included follow-up assessments. The sample size of the intervention group was less than 20 in 11 of the studies. It was also reported that twelve of the studies lacked strategies to assess to what extent the therapists complied with manualised programmes (fidelity of implementation). Notwithstanding these methodological limitations, consistent reports of small to medium effect sizes attest to the potential benefits of psychological interventions to distressed and depressed parents of children who have DD (Singer et al., 2007).

1.6.1 Psychological intervention programmes for distressed parents of children who have ID and behavioural difficulties

A summary of a small number of studies that have focused on the use of psychotherapy with parents of children and adults who have developmental disability is presented in Table 3:

Table 3:

Psychotherapy Studies: Distressed Parents of Children and Adults who have Developmental Disability and Behavioural Difficulties

Study	Study Design	Psychotherapy or counselling	Outcome and appraisal of methodological limitations
Hudson et al., 2003	<p>39 participants completed a manualised programme, Signposts. Participants were divided into the following groups: group intervention (n=13); telephonic consultations and instructions (n=5); and self-study and instruction with support (n=7). 26 participants were part of the control group.</p> <p>The following psychometric tests were used:</p> <ul style="list-style-type: none"> - Parenting Sense of Competence Scale - The Depression and Anxiety Stress Scale - Parenting Hassles Scale - Developmental Behaviour Checklist - Consumer Satisfaction Scale <p>The Statistical Package for Social Sciences was used to analyse data. Analysis of co-variance was used to measure changes</p>	<p>Signposts included:</p> <ul style="list-style-type: none"> - Psychoeducation to parents - The replacement of undesirable behaviours with incompatible or competing behaviours. - Parental skills training - Family intervention and parental stress management. 	<p><u>Outcome:</u></p> <p>The following post-intervention benefits were reported by the participants who completed the Signposts programme:</p> <ul style="list-style-type: none"> - Increased parental self-efficacy. - Lower levels of parental stress. - The children's behaviour was reported as being less disruptive. <p><u>Strengths:</u></p> <ul style="list-style-type: none"> - The use of a control group and follow-up assessment. - The use of a comprehensive battery of psychometric tests. - The study represented clinical research in real-life setting. <p><u>Limitations:</u></p> <ul style="list-style-type: none"> - Lack of randomisation. - A significant number of participants who started intervention did not complete the programme.
Plant & Sanders, 2007	<p>74 Western Australian parents (including couples) of young children who had DD and behavioural difficulties were divided into 3 groups:</p> <ul style="list-style-type: none"> - Stepping Stones Triple P: focus on parental skills training and ways to enhance parental coping (n=24), i.e., SSTP-S. - Stepping Stones Triple P: focus on parental skills training alone (n=26), i.e., SSTP-E. - Control group (n=24). <p>The following psychometric tests were used:</p> <ul style="list-style-type: none"> - Abbreviated Dyadic Adjustment Scale. - Caregiving Problem Checklist. - Depression, Anxiety and Stress Scales. - Developmental Behavior Checklist: Parent Version. - Eyberg Child Behavior Inventory. - Parenting Sense of Competence Scale. - Parenting Scale. - Revised Family Observation Schedule. - The Client-Satisfaction Questionnaire. - Vineland Adaptive Behavior Scales. 	<ul style="list-style-type: none"> - 10 individual sessions were conducted with participating couples or individuals. - Parental skills training focused on behavioural strategies to manage child's behaviour, e.g., effective communication, time-out and distraction (SSTP-S and SSTP-E). - The coping skills programme focused on psychoeducation, the use of friends, family and acquaintances to bolster support, problem-solving strategies, and ways to enhance active-listening (SSTP-E). 	<p><u>Outcome:</u></p> <ul style="list-style-type: none"> - Statistically-significant reductions in the child's behavioural difficulties (SSTP-S and SSTP-E). - Intervention did not facilitate significant reductions in parental stress (SSTP-S and SSTP-E). - At 1-year follow-up, the SSTP-E programme was more effective than SSTP-S in reducing the child's behavioural difficulties. <p><u>Strengths:</u></p> <ul style="list-style-type: none"> - The inclusion of a control group and follow-up assessment. - The use of a comprehensive battery of psychometric tests. - The intensive use of individual sessions to facilitate change in both groups. <p><u>Weaknesses:</u></p> <ul style="list-style-type: none"> - While participants were randomly assigned into 3 groups, the recruitment process made use of volunteers to obtain an adequately-sized sample. The parents who volunteered to take part in the study might have been more motivated than parents who decided not to participate. - The control group did not

	Analysis of covariance was used to compare pre-, post- and follow-up assessment. <i>t</i> -statistics measured the effectiveness of the two interventions.		complete 1-year follow-up assessment.
Roberts, Mazzucchelli, Studman, & Sanders, 2006	<p>Queensland parents of 47 young children participated in a randomised controlled trial comprising an intervention group of 24 families and a control group of 20 families. Only 29 families completed intervention.</p> <p>The following tests were used:</p> <ul style="list-style-type: none"> - Client Satisfaction Scale. - Depression, Anxiety and Stress Scales. - Developmental Behavior Checklist: Parent Version. - Family Observation Schedule – Revised. - Parenting Scale. - Stanford-Binet Intelligence Scale (4th edition). - Vineland Adaptive Behavior Scales. <p>A mixed-model multivariate analysis was used to measure the impact of the Stepping Stones Triple P.</p>	The Stepping Stones Triple P was used to provide parental skills training to manage their children's behavioural difficulties including aggression.	<p>Outcome:</p> <ul style="list-style-type: none"> - Significant reductions in the behavioural difficulties of children whose mothers participated in the intervention groups. - Participating fathers did not report significant improvement in their children's behaviour, but their baseline-reports of behavioural difficulties were lower than maternal reports. - Intervention did not significantly reduce high levels of parental stress. <p>Strengths:</p> <ul style="list-style-type: none"> - The use of a randomised controlled trial, albeit with relatively small sample size. - The use of a comprehensive battery of psychometric tests. <p>Limitations:</p> <ul style="list-style-type: none"> - The small sample size, especially the number of participating fathers (n=10). - Significant number of participating families that started intervention did not complete post-assessment and follow-up assessment.
Roux, Sofronoff, & Sanders, 2013	<p>The study employed a randomised controlled trial as study design. The Stepping Stones Triple P programme was used with parents of children who had DD and behavioural difficulties. The experimental group comprised 28 participants and the control group had 24 participants. Pre-, post- and follow-up assessment was conducted with the use of the following psychometric tests:</p> <ul style="list-style-type: none"> - Client Satisfaction Questionnaire. - Family Background Questionnaire. - Depression Anxiety Stress Scales - Developmental Behavior Checklist. - Eyberg Child Behavior Inventory. - Goal Attainment Questionnaire. - Parent Problem Checklist. - Parenting Scale. - Relationship Quality Index. <p>Multivariate analysis measured different outcomes between the experimental and control group.</p>	The Stepping Stones Programme provided parental skills training in the form of 25 ways to manage their children's behavioural needs.	<p>Outcomes:</p> <ul style="list-style-type: none"> - The experimental group reported statistically significant reductions in the frequency of the child's behavioural difficulties. - Parental interaction with the child improved significantly. - Parental mental health did not improve in a statistically-significant manner at post-assessment or follow-up. <p>Strengths:</p> <ul style="list-style-type: none"> - The use of a randomised controlled trial design. - The comprehensive battery of tests that were used to measure therapeutic change. <p>Limitations:</p> <ul style="list-style-type: none"> - The authors recommended that future research should use behavioural methods besides the use of psychometry to quantify target behaviours on baseline, which in turn would allow the measurement of change over time.
Singh, Lancioni, Winton, Singh, Curtis, Wahler, & McAleavey, 2007	4 mothers of children who had DD participated in a multiple-case design. <i>Baseline observations</i> (Phase 1) of between 3 and 12 weeks were	The study trained the 4 participating mothers in the basic principles and practices of mindfulness when facing their children's behavioural difficulties.	<p>Outcomes:</p> <p>The average number of the children's aggressive episodes decreased as follows:</p> <ul style="list-style-type: none"> - First case study: 33% from

	<p>followed by <i>Mindfulness training</i> (Phase 2) which lasted up to twelve weeks. <i>Mindfulness practice</i> (Phase 3) continued after training for 1 year in each case.</p> <p>The following behavioural observation methods were used to measure the child's aggression:</p> <ul style="list-style-type: none"> - Participating mothers used the Palm Personal Digit Assessment to establish the frequency of their children's aggression. Fathers also rated the frequency of such behaviours in order to establish inter-rater reliability. - Behavioural analysts observed the relationship and interaction between mother and child in a controlled environment for 15 minutes each week (observation was done on 22 occasions in each case). Interaction was rated as positive, neutral or negative. Inter-rater reliability was established between the two raters. - The participating mothers also provided subjective units of distress (0 -100) on the following 3 measures: <ul style="list-style-type: none"> - Parental satisfaction. - Satisfaction with regard to parent-child interaction. - Whether mindfulness had been displayed whilst the child was displaying aggression. - One psychometric test, the Parenting Stress Index, was used to measure parental stress at different intervals before, during and after intervention had been completed. - Individual interviews were also conducted with the participating mothers. 		<p>Phase 1 to Phase 2; and 87% from Phase 2 to Phase 3.</p> <ul style="list-style-type: none"> - Second case study: 26% from Phase 1 to Phase 2; and 94% from Phase 2 to Phase 3. - Third case study: 30% from Phase 1 to Phase 2; and 91% from Phase 2 to Phase 3. - Fourth case study: 36% from Phase 1 to Phase 2; and 88% from Phase 2 to Phase 3. <p>- In all four cases, the number of positive interactions between mother and child increased significantly after training had been completed. Likewise, the number of negative interactions decreased significantly between baseline assessment (Phase 1) and the completion of mindfulness practice (Phase 3).</p> <p>Towards the end of Phase 2 and throughout Phase 3, improved subjective ratings were reported in the three domains that were measured.</p> <ul style="list-style-type: none"> - Parental stress was moderately reduced amongst all the participants. <p><u>Strengths:</u></p> <ul style="list-style-type: none"> - The use of a rigorous behavioural design that included baseline assessment over multiple weeks and the systematic measurement of behaviours over 65 weeks. - The use of 2 qualified behaviourists to conduct observation in order to obtain inter-rater reliability of over 90%. <p><u>Limitations:</u></p> <ul style="list-style-type: none"> - The small number of participants. - The lack of randomisation and the possibility of various spurious variables that could account for the positive behavioural changes that were reported.
--	---	--	--

1.6.2 Psychotherapy process research with families of children who have DD

Earlier psychotherapy research from the 1930s to the 1950s investigated whether psychotherapy was able to facilitate psychological change. With the advance of behaviour therapy, a second generation of psychotherapy research emerged in the 1960s. Psychotherapy research correspondingly started to investigate the efficacy of specific behavioural interventions such as graduated exposure to treat specific psychological conditions, e.g., phobias. Behavioural research was also characterised by enhanced methodological rigour in the form of randomisation and the use of a control group (Pachankis & Goldfried, 2007). The third group of psychological research emerged from the behavioural field in the 1980s: randomised controlled trials became the most authoritative research design of psychotherapy research. RCTs measure the efficiency of one psychotherapeutic intervention against another (Pachankis & Goldfried, 2007).

Although RCTs employ sophisticated empirical methods to establish the broad efficiency of a psychological intervention to treat particular psychological problems or DSM disorders, the external validity of RCTs remain problematic to practising psychotherapists (e.g., Kazdin, 2007). More specifically, the statistical quantification of therapeutic efficiency generally does not inform clinical practice at specific points of intervention; and the role of contextual factors in the life of a specific client could have a profound and pervasive influence on the person's ability to achieve therapeutic goals (Edwards et al., 2004; Kazdin, 2007).

At its most basic level, the distinction between psychotherapy outcome research and process research could be described as follows: whereas outcome-based research uses statistical methods to ascertain whether an intervention facilitated therapeutic

change, process research describes in what way and by what means psychotherapy works (Pachankis & Goldfried, 2007).

Although traditional psychotherapy process research has examined and described the complex process of psychotherapy within and across each session, contemporary psychotherapy process research has also strived to identify and describe a plethora of psychotherapy structures, workings or events that facilitate or obstruct therapeutic change (Pachankis & Goldfried, 2007). Psychotherapy process research therefore investigates a range of factors to describe the manner in which participants respond to therapeutic intervention. Pachankis and Goldfried (2007, p. 762) have described some of the factors that influence a participant's response to psychotherapy intervention as "characteristics of the client, therapist, relationship, and intervention that are likely to influence change in therapy."

Gelo and Salvatore (2016) succinctly describe how psychotherapy process research attempts to capture essential agents of change at play within and between the therapist, client and their therapeutic relationship:

. . . it comprises time-dependent biographical, historical, and developmental processes; it is complex because these processes are multidimensional and multidetermined, manifesting themselves in very different ways at different levels, and resulting from multiple factors reciprocally interacting with each other. As a consequence of this, psychotherapeutic change is rarely linear, steady, and continuous, but rather nonlinear, sudden, and discontinuous. (p. 1)

A growing number of studies have explored aspects of psychotherapy process when conducting family research among children and adults who have developmental

disability (e.g., Anclair & Hiltunen, 2014; Baldwin, 2014; Carlson, Armitstead, Rodger, & Liddle, 2010; Haugstvedt, Graff-Iversen, Bukholm, Haugli, & Hallberg, 2013; Ramisch, Timm, Hock, & Topor, 2013; Solomon & Chung, 2012). While extensive discussion is beyond the limitations of this study, a selection of these studies will now be briefly described to demonstrate how some of these intervention studies have explored therapeutic process when conducting ID family research.

Baldwin (2014) has used a single case-design to explore the role of therapeutic ruptures between psychotherapists and parents when shame and guilt hinder the parent's willingness to allow their children continued access to psychological intervention. Baldwin has emphasised the strengthening of the therapeutic alliance and facilitation of a reflexive therapeutic space to provide the parent the opportunity to gain insight into the impact of guilt and shame on her therapeutic alliance with the psychotherapist. The findings should be interpreted with caution: the case study did not employ strategies to enhance rigour, e.g., strategies to increase credibility, transferability and confirmability (Baldwin, 2014).

A recent Swedish study employed two single cases to describe the use of CBT with two mothers of children who had autism. In both cases, conceptualisations provided relevant contextual information; and the course of treatment was also described. In the first case study, the participant identified the following psychological stressors that led to depressive symptoms: her status as a refugee, adjustment problems in Sweden, the child's repetitive verbalisations and a relative lack of support from an absent partner. On a cognitive level, the participant also presented with beliefs of inadequacy. The case study described how psychoeducation was used to increase a sense of control over the child's behavioural difficulties. Based on therapeutic

intervention, the participant also took up some of the enjoyable activities she used to do before her energy became depleted (Anclair & Hiltunen, 2014).

In the second case study, the participating mother reported high levels of anxiety because of demanding caregiving tasks. The study included contextual information, e.g., her caregiving responsibilities precluded full-time employment, which in turn increased her anxiety. The case study describes how psychotherapy process elicited the mother's repetitive monitoring of her child's behaviour and reassurance-seeking behaviour aimed at lowering her own anxiety. Cognitive strategies were followed to modify negative self-statements about being a bad mother. The study also described how basic assertion training and problem-solving lowered negative perceptions about her capacity as a caregiver (Anclair & Hiltunen, 2014).

Carlson and her colleagues (2010) used semi-structured interviews to explore the perceptions of nine parents regarding their participation in therapeutic interventions in a community-based setting in Australia. Thematic analysis elicited themes that included the following: Parents highlighted the benefit of receiving multidisciplinary input when their children were in early childhood, especially if such input was delivered in the educational setting of the child or at home. The participants also emphasised that they wanted to take part in the planning and implementation of formal support programmes for their children. Parents considered the provision of educational books and information about their children's disability as valuable multidisciplinary interventions. The overall attitude of services, including the organisation's willingness to support their children, was cited as an important factor when family support is provided (Carlson et al., 2010). The study therefore elicited *how* the rendering of family support by means of specific multidisciplinary interventions and processes within ID services could assist families. While the

number of participants in this study represented only a small number of parents, the use of numerous strategies to enhance qualitative rigour is considered to be a methodological strength (Carlson et al., 2010).

In a larger qualitative study, semi-structured focus groups were held with 67 parents of children and adolescents who had a disability. The parents participated in counselling groups that were based on gestalt therapy principles. Grounded theory was used to analyse findings (Haugstvedt et al., 2013). The following themes were identified: First, parents described an increased need to effectively verbalise their feelings and thoughts; they also appreciated the value of being actively listened to by other parents and the facilitators. Second, parents reported that they valued the positive aspects of their lives: They started using words they had not used before to try and capture the essence of their experiences; this process led to novel discoveries and an increased awareness of their parental experiences. Third, their increased self-awareness from the process of counselling facilitated a renewed focus on strategies to decrease parental stress in a manner that was congruent to their own value systems. Fourth, the more tangible strategies that they started to implement following counselling were often introduced in incremental steps. Last, the counselling space facilitated a process of self-awareness which expanded their vision of possible coping strategies to deal with caregiving demands (Haugstvedt et al., 2013).

In qualitative terms, the abovementioned study had a large sample size. The detailed information that was obtained about counselling process, from the perspective of participants, could also be considered as one of the study's strengths. The authors identified the following methodological limitations: First, the authors pointed to the possibility that participants might have deliberately described positive

experiences to please the interviewers, who also conducted the counselling sessions. Second, although not a limitation per se, the authors reiterated that their focus during the interviews was on descriptions of the counselling process and not on qualifying the effectiveness of the counselling programme. They therefore recommended that future qualitative studies should also employ strategies to formally assess the quality of counselling programmes from the perspective of participants (Haugstvedt et al., 2013).

1.7 Towards a Research Agenda: A Critical Appraisal of the Literature Review

The literature review has covered a considerable body of contemporary family research of children and adults who have DD. The overview also focused on the most salient behavioural difficulties among people who have DD and the use of different psychotherapeutic and behavioural approaches to address parental stress and depressive symptoms among mothers and fathers of children who have DD. It was also interesting to note that parents of adults who have DD often reported novel developmental challenges that were associated with the transitional period between midlife and old age (e.g., Heller et al., 2007; Seltzer et al., 2011). Furthermore, a large number of studies have found that parental stress among parents of children and adults who have DD are elevated if the child has pronounced behavioural difficulties (Blacher & McIntyre, 2006; C. E. Hill & Rose, 2009; Kim et al., 2003).

I will now critically appraise how the literature review informed the study's research agenda:

- First, notwithstanding the fact that there exists a large body of research that has investigated the phenomenon of parental stress or depressive symptoms among parents of children or adults who have DD and behavioural difficulties, most of

these studies adopted quantitative research criteria (e.g., Emerson et al., 2006; Emerson & Llewellyn, 2008; Hassall et al., 2005). Large population-based studies have found associations between maternal distress, maternal education level and socio-economic position, however, more research is needed to describe and explain *how* contextual factors such as poverty and education impact on maternal well-being among parents of persons who have DD (Emerson & Hatton, 2009).

- Second, it was noticeable that the vast majority of parental psychotherapeutic or behavioural interventions were based on either randomised or non-randomised controlled studies (e.g., Hastings & Beck, 2004; Singer, 2006). The valuable contributions of these studies lay in their consistent findings that psychotherapy and parental skills training could lower high levels of parental stress or depressive symptoms among parents of children and adults who have DD, with or without behavioural difficulties.

Edwards, Dattilio and Bromley (2004, p. 591) have seen an opportunity for smaller case studies with predominantly qualitative research designs to augment the findings of larger outcome-based treatments: "In the design of RCTs, steps are taken to maximize the possibility of obtaining evidence about treatment outcome. But this limits their usefulness for testing propositions about the processes involved in achieving outcome". The authors also argued that researchers and psychotherapists have a keen interest in understanding the *process* of intervention: if it was found that psychotherapy is effective in reducing different negative psychological states among parents of children who have DD,

how could clinicians apply these findings in real-life clinical settings and what therapeutic processes are involved that led to change?

- Third, almost all of the larger psychotherapy and population-based studies in the DD family research field were conducted in high-income countries (Emerson et al., 2006; Ha et al., 2008; Seltzer et al., 2011; Singer, 2006; Singer et al., 2007). Smaller studies are therefore required to explore the dynamics of contextual factors and the applicability of therapeutic interventions among people who live in middle-income countries such as South Africa.
- Last, as described, the use of the umbrella term "behavioural difficulties" or "challenging behaviour" is problematic because different forms of problem behaviours often have different aetiological mechanisms and consequences for the person who displays such behaviours and her caregivers (e.g., Cooper et al., 2009; Royal College of Psychiatry, 2001).

The current study adopted a research agenda that considered the findings that were delineated in the literature review. As I will describe in the next chapter, the study explored the use of CBT among a small group of ageing mothers whose adult children presented with a specific behavioural phenomenon: aggression. The participants experienced high levels of parental stress. The research agenda was informed by the need to explore the contextual factors in the lives of the participating mothers. Moreover, the research agenda had to be sensitive to such factors in a real-life South African clinical setting with a specific mandate.

CHAPTER TWO: RESEARCH METHODOLOGY

2.1 Research Question

2.1.1 The reformulated research question

The original research question regarding the use of CBT with a group of mothers whose children had ID and aggression was reformulated from its quantitative set of objectives, hypotheses and aims to a broader qualitative focus. The study evolved into an in-depth exploration of the complex process of psychotherapy and its contextual embeddedness after I had become increasingly aware of the pervasive role of contextual factors in maintaining and perpetuating parental stress and maternal depression across different case studies.

The research question was accordingly changed to the following:

What are the caregiving experiences of a group of South African mothers of adults who have ID and aggression who attend a specialised mental health service?

My epistemological assumptions of the word *experience* were grounded in a theoretical understanding of the concept in social-constructionism and existential-phenomenology (Frie, 2003). Experience signifies a very different meaning from the ontological representation of the word in positivist and post-positivist paradigms (Frie, 2003).

Appendix A contains an account of my epistemological thinking behind the decision to use "*caregiving experiences*" in the research question.

2.1.2 The use of CBT was not invalidated by the reformulated research question

While adopting a broader research agenda to allow for a comprehensive investigation of contextual variables and psychotherapy process, this study also continued to explore the use of CBT with the participating mothers.

2.2 Study Design and Research Methodology

2.2.1 Defining case study research

The study consisted of a series of single cases. Case study research is often poorly understood and the scientific world has not reached consensus as to whether this form of research represents a research methodology or an epistemological paradigm that attaches value to the generation of knowledge through narratives or storytelling (Chamberlain, Camic, & Yardley, 2004).

Case study research is defined as “intensive, detailed, in depth study, examination or investigation of a single unit – the case – where the focus is on the particular. . .” (Luck, Jackson, & Usher, 2007, p.104). Likewise, Petermann and Müller (2001, p. 41) describe a case study as a discrete element of analysis, or “a range of different research strategies that share one common feature: the unit of observation ($n = 1$) cannot be divided any further”.

2.2.2 The advantages of case studies

- *Generating detailed and in-depth information about therapeutic process in a specific case:*

Well-designed psychotherapy case studies have the potential to facilitate the in-depth exploration of the psychotherapy process involving a single participant (Chamberlain et al., 2004; McLeod, 2012). Narrative descriptions capture

meaningful therapeutic events as they unfold over the course of therapy (McLeod, 2012).

Larger intervention studies often use cross-sectional designs to measure therapeutic efficacy before and after psychotherapy. The potential usefulness of case study research lies in its ability to describe therapeutic process over the course of time (Edwards et al., 2004; Dattilio, 2006; McLeod, 2012).

- *Eliciting contextual information in psychotherapy research:*

The provision of detailed narrative descriptions allows the reader to familiarise himself with many of the relevant contextual factors across different cases, e.g., the personal and social context of the participant, specific service-design characteristics, and the experience of the therapist or client in the therapy relationship (Edwards, 2007; Eells, 2007; Kazdin, 2007; McLeod, 2012).

Edwards and his colleagues (2004) proposed that case study research could be used to augment large efficacy studies by providing in-depth information about psychotherapy process and the role of contextual variables.

- *"Particularization" and inductive reasoning:*

When conducting a series of single cases, deductive reasoning is often used to analyse the research material across different cases (McLeod, 2012; Simons, 2009). Knowledge is also generated through "particularization" or inductive reasoning, i.e., to investigate complex inter- and intrapersonal processes within a particular case. "Particularization" is especially informative in cases that represent rare, unusual or idiosyncratic clinical presentations (Flyvberg, 2005; Simons, 2009).

- *A flexible methodological design:*

Recent case study research often integrates qualitative and quantitative methods in a mixed methods design (Edwards et al., 2004; McLeod, 2012; Silverman, 2013; Yin, 2014).

Case studies also offer procedural flexibility. The identification of procedural shortcomings in earlier cases provides opportunities to modify and streamline procedures in subsequent cases (Barlow, Nock, & Hersen, 2009; N. Hayes, 2000; Willig, 2008).

- *The generation of theoretical knowledge in the absence of a comprehensive evidence-base or expansive theory:*

McLeod (2012) has cited classical case studies that were used by pioneers in the psychotherapy field such as Sigmund Freud, Harry Sullivan and Aaron Beck, to demonstrate the usefulness of cases when new theoretical knowledge was generated in areas of psychotherapy that lacked a comprehensive evidence-base.

Case study research, with its emphasis on longitudinal narrative descriptions, is better-positioned than cross-sectional designs and outcome studies to formulate new theories or expand existing theoretical constructs (Barlow et al., 2009; N. Hayes, 2000; McLeod, 2012; Willig, 2008).

- *The use of case studies to facilitate clinical training and inform professional ethics:*

Clinical case studies and vignettes are commonly used to demonstrate effective clinical practice and facilitate discussion regarding ethical dilemmas. Case studies are also employed to describe interesting or unusual clinical

presentations. Knowledge is therefore transferred between professionals; and cases are also used for clinical training purposes (McLeod, 2012).

- *The cost-effectiveness of case studies in clinical settings with limited fiscal and human resources:*

The cost implications of large randomised controlled outcome studies could be prohibitive, especially in low- and middle-income countries (Dattilio, Edwards, & Fishman, 2010). In clinical settings with limited resources, clinicians may not have the training opportunities that would enable them to comply with manualised treatment protocols (Dattilio et al., 2010). Case study research is considered as more affordable and practical in busy clinical settings, because it typically involves one participant and one researcher (Simons, 2009).

2.2.3 Criticism against case study research from different paradigmatic perspectives: The potential methodological pitfalls of poorly-designed case studies

Case study research has been criticised by positivist and post-constructionist researchers. Such criticism tends to be based on the underlying paradigmatic and epistemological assumptions of the researchers (Edwards et al., 2004; Hollway, 2015, 2016; Hollway & Jefferson, 2013; McLeod, 2012).

Epistemology is understood as theoretical assumptions about knowledge (Hollway, 2015). In the context of research, epistemology specifies "not only what knowledge is and how to recognise it, but who are the knowers and by what means someone becomes a knower or expert." (Hollway, 2015, p. 140).

Different paradigmatic positions will at times hold very different views about the specific methods that are employed in case studies with regard to issues regarding statistical validity, subjectivity, etc.:

- Unsurprisingly, many positivist researchers have criticised traditional case studies by describing such research as anecdotal reports with limited scientific and empirical properties (Dattilio, 2006; Dattilio et al., 2010; Kratochwill, 1992; Silverman, 2013).
- McLeod (2012) argues that case study research is not an acceptable method for either efficacy studies or studies that aim to inform the implementation of public health policies. Psychotherapy outcome research would be better served by RCTs or at least non-randomised controlled studies.

As a proponent of qualitative case studies, Schofield (as cited in Chamberlain et al., 2004) describes the overarching objective of qualitative case study research as follows:

The goal is not to produce a standardized set of results that any other careful researcher in the same situation or studying the same issue would have produced. Rather it is to produce a coherent and illuminating description of and perspective on a situation that is based on and consistent with detailed study of that situation. (p. 97)

- Diverse paradigmatic criticism has been directed against case studies that failed to formally address epistemological concerns about researcher subjectivity (Hollway, 2015, 2016; Hollway & Jefferson, 2013). In post-positivism, social-constructionism or interloping positions between the two paradigms, it is argued that poorly-designed case studies offer limited opportunities for an external

examiner or supervisor to evaluate the credibility, trustworthiness or reliability of findings:

- From a post-positivist perspective, qualitative case study research is often criticised if methodological strategies aimed at enhancing the credibility and trustworthiness of findings are not incorporated in the research design (e.g., Edwards et al., 2004).
- Towards the more extreme end of social constructionism, the personal engagement of a researcher who is also a clinician may raise questions whether the data analysis represents a possible objectification of the participant (Frie, 2003).
- Social-constructionist criticism will not be directed against the use of subjectivity, but rather the use of subjectivity in the relative absence of researcher reflexivity (Hollway, 2015).
- Conversely, in psychoanalytic paradigms, researcher subjectivity is conceptualised as an important vehicle to generate knowledge about complex human processes (Hollway, 2015; Hollway & Jefferson, 2013).

A psychoanalytically-informed epistemology will understand many such processes as representing unconscious motivations that are only partly accessible through the use of language and research methods such as interviews (Hollway, 2015). Criticism would be directed against case studies that did not employ reflexivity to deal with negative, unconscious countertransference reactions from the researcher, especially when such reactions could be explained by personal opinions, experiences and events within the researcher's life (Hollway, 2015).

2.2.4 Balancing the strengths of case study research against legitimate criticism: The study's rationale for using a series of single cases

I adopted a series of single cases as the methodological design of this study because of the methodological advantages that were described in the previous section. I will now apply some of the advantages to the research design:

- Rich, in-depth descriptions of complex psychotherapy processes were produced in the narratives of each case study.
- The procedural flexibility of case study research afforded opportunities to change aspects of the research method such as the research question.
- There is a paucity of studies that have explored the use of individualised psychological intervention for distressed South African mothers of adults who have ID and aggression.

Using the search words *caregiving, parents, families, intellectual disability, learning disability, developmental disability, mental retardation, challenging behaviour*, problem behaviour** and *psychotherapy*, a database search comprising Pubmed, Academic Search Premier and PsychINFO between 1990 and 2014 produced only one relevant study that was conducted in the Limpopo Province of South Africa (Sandy et al., 2013). This research initiative consisted of three case studies that explored the caregiving experiences of families of adolescents who have ID and did not use psychotherapy as the vehicle of research (Sandy et al., 2013).

As described earlier, one of the strengths of case study research lies in its ability to elicit and describe social and personal context (e.g., McLeod, 2012). In an under-studied field in local research, a case study design was able to generate narrative descriptions of the context in which a group of

South African mothers presented with high levels of parental stress and inadequate coping.

- A case study design with manageable cost implications and a realistic time frame also lent itself to real life research in a busy specialised intellectual disability service with finite human and financial resources.

A larger intervention study would have made valuable contributions in terms of efficacy and aspects of specific therapeutic methods within CBT, but we had inadequate human and fiscal resources to pursue a project of this nature. Besides postgraduate teaching responsibilities and the provision of clinical supervision to intern psychologists and psychiatric registrars, I was one of only two psychotherapists responsible for the management of tertiary-level referrals of adults with ID and complex mental health needs in the Western Cape, a province with more than 6 million people.

Notwithstanding the abovementioned advantages, the design also had to be safeguarded against potential methodological pitfalls that are associated with poorly-designed cases that lack scientific rigour.

2.2.5 Positioning the current study within contemporary psychotherapy case study research: The different forms of case studies

Recent advances in case study research led to the formulation of methodological standards that encapsulate the characteristics of rigorous case study designs (Dattilio, 2006; Edwards et al., 2004; McLeod, 2011; 2012; Silverman, 2013; Yin, 2014). However, there are different forms of case studies with very different study designs (e.g., Fishman, 2005; McLeod, 2011; 2012). It is for that reason important to briefly describe the different formats of single case designs before I discuss the current study's research design:

- **Single-case designs** ($n = 1$) are grounded in applied behavioural analysis and are characterised by repeated measurements of discrete psychological constructs at different intervals of intervention (McLeod, 2012).

Single-case designs attempt to reduce researcher subjectivity by employing an experimental research design in psychotherapy case studies. Observation schedules and a time-series analysis are used to establish the outcome of different reinforcement schedules on discrete behaviours or cognitive constructs (McLeod, 2012).

- The primary objective of **theory-building case studies** is to generate theoretical knowledge within psychotherapy (McLeod, 2012).

Contemporary theory-building case studies use qualitative research strategies that provide the analysis with higher levels of credibility and trustworthiness (McLeod, 2012).

- Similar to single-case designs, **pragmatic case studies** track therapeutic change by measuring different psychological constructs at different intervals of intervention (Dattilio et al., 2010; Edwards et al., 2004; Eells, 2007; McLeod, 2012; McLeod & Elliott, 2011). Pragmatic case studies use a mixed methods design that combines time-series analysis with the qualitative analysis of interviews and/or psychotherapy sessions (Fishman, 2005; 2013; Edwards et al., 2004).

Fishman (2005, 2013) proposed a structured format to direct the researcher's study design. He also recommended that researchers use qualitative strategies to enhance the rigour of their analysis.

- As implied by its name, a **narrative case study** produces stories or narratives to generate knowledge through the reader's engagement with the text (McLeod, 2012). Research material includes diaries and autobiographical descriptions; and narrative case studies tend to omit qualitative strategies that are aimed at enhancing rigour through external scrutiny (McLeod, 2012, 2013).

McLeod (2012) points to the importance of distinguishing narrative case studies from case narratives: the former represents a specific study design with a discernible postmodernist epistemology while the latter underlie all formats of case studies. Case narratives represent a fundamental characteristic of all case study research: story-telling and knowledge-generation through the use of language (McLeod, 2012).

- **Psychosocial case studies** represent one of the most recent developments in case study research (Hollway, 2015; 2016; Hollway & Jefferson, 2013). Proponents of psychosocial case studies are directly opposed to the bracketing of researcher subjectivity. Instead, researchers are encouraged to use their subjectivity and their specific clinical expertise to make sense of individual cases (Hollway, 2015; Hollway & Jefferson, 2013).

Psychosocial case studies do not eschew the use of language to generate knowledge in research through interviews and other data analysis methods. Participants in case study research are conceptualised as persons that are "the products of their own unique psychic worlds and a shared social world" (Gadd & Jefferson, 2007, as cited in Hollway & Jefferson, 2013, p. xiii). Criticism in this context is also directed towards

dualistic discourses within post-positivist case study research, i.e., when (internal) psychological processes are categorically separated from their (external) social context (Hollway, 2015).

Because researchers are inter-subjectively related to participants through their interaction, meaning is correspondingly derived not only from linguistic discourses but also from the researcher's efforts to make sense of those conversations. Moreover, language provides a simplified and imperfect tool to generate knowledge (Hollway, 2015).

The participant signifies meaning not only through what is said, but also what remains unsaid, at times non-verbally acknowledged, or picked-up by means of the researcher's observations of inconsistencies in linguistic discourse (Hollway, 2015).

The limitations of a participant's language to accurately delineate complex inner processes whilst simultaneously negotiating broader social context require skilled researchers to engage with their own subjectivity to make the research meaningful (Hollway & Jefferson, 2013; Hollway, 2015, 2016).

Hollway (2015) proposes that skilled psychologists should use their acquired knowledge of interpersonal and intrapersonal processes to analyse the overt content of their co-constructed engagement with participants. Researchers should also be sensitive to unconscious processes that are at play within and between the researcher and participant (Hollway, 2015, 2016; Hollway & Jefferson, 2013).

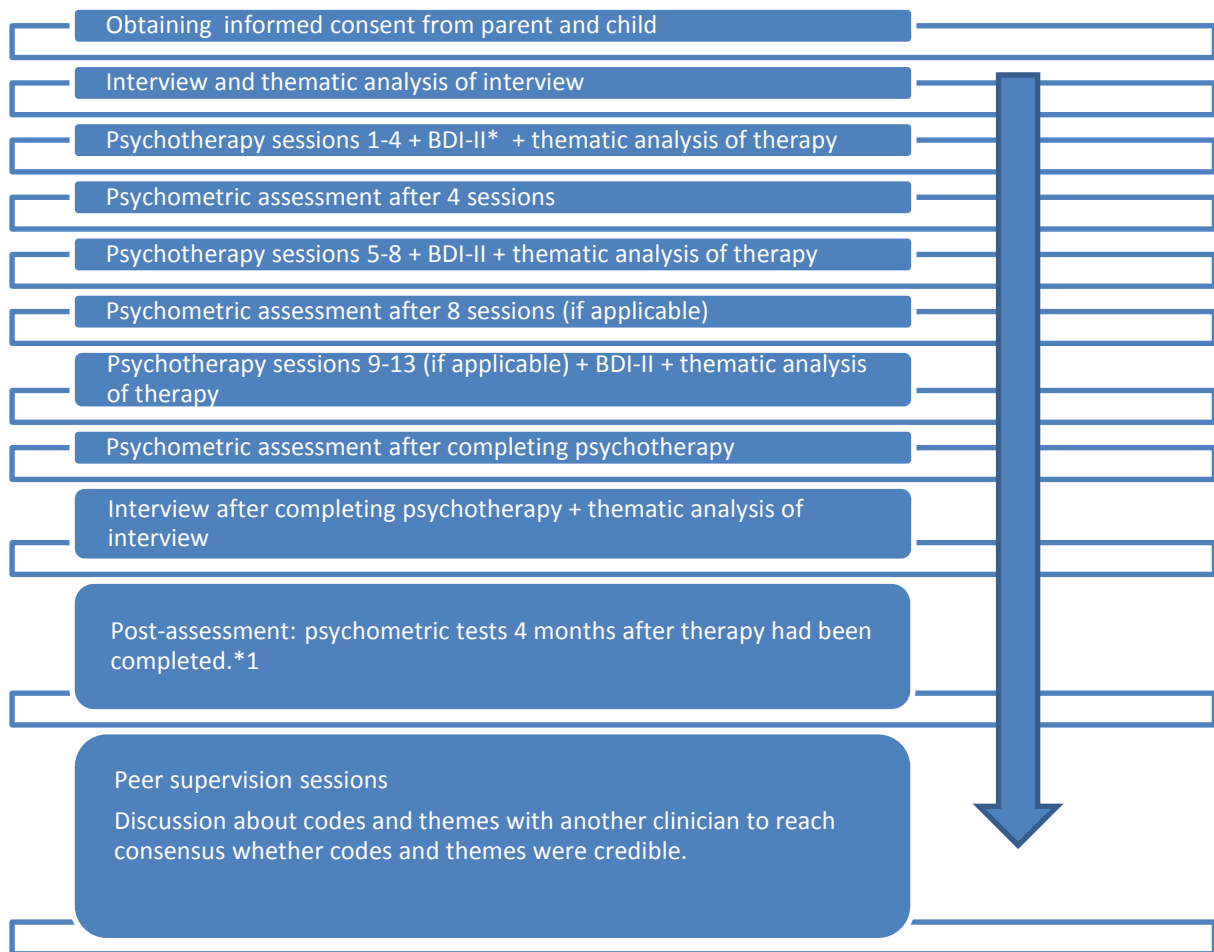
A researcher's engagement with his own subjectivity should not result in anecdotal and biased reports. Psychosocial case studies require

external credibility and researchers are encouraged to pursue peer supervision opportunities. Researchers should also engage in ongoing reflexivity (Hollway, 2015; Hollway & Jefferson, 2013).

2.2.6 The study's use of a mixed-method case design

When planning and implementing the study design, I considered the advantages of case study research against the criticism of the different forms of case study designs. With regard to differences between pragmatic case studies, single-case designs and narrative case studies, it was imperative that I aligned the study's design with existing guidelines and recommendations from expert opinion in contemporary case study research. A creative and innovative approach was required to produce a series of case studies that were either qualitatively rigorous or embedded in firm experimental principles. The study design of each case study is presented in Figure 3.

Figure 3. The study design of each case



* The BDI-II is a clinical self-report scale that was introduced in the second case study after measurements in the first case failed to comprehensively assess depressed mood.

*1 The 4-month post-assessment of one case study generally overlapped with the intervention phase of the next case because of practical considerations and time-constraints.

The study design applied the principles of pragmatic case studies in three fundamental ways: First, as illustrated in Figure 3, each case study adopted a mixed methods design. Psychometric tests were used at various intervals of psychotherapy; and thematic analysis was used to analyse the psychotherapy sessions and interviews that were scheduled before and after the intervention phase of each case (Edwards et al., 2004; Hanson, Creswell, Clark, Petska, & Creswell, 2005). Second, as described below, I applied various qualitative strategies that were

aimed at enhancing rigour and external credibility. Last, as recommended by Edwards and his colleagues (2004), I produced extensive narratives to describe the therapeutic process of each case study, thereby allowing the reader to use their own frame of reference and knowledge to assess the credibility of the thematic analysis. Importantly, the narratives of each session therefore represented a strategy to enhance credibility (McLeod, 2012).

Wendy Hollway's (2015) work on psychosocial case studies also had a significant influence on the study design: First, as I will describe later in this chapter and in Appendix A, external validity was not achieved by bracketing my subjectivity during analysis. Besides ongoing reflexivity, peer supervision was arranged to create opportunities to interrogate the themes that emerged from thematic analysis. Peer supervision was also used to facilitate ongoing reflexivity. Last, psychosocial case study research emphasises the importance of contextual and social factors, which firmly resonated with my focus on psychotherapy process (Hollway, 2015).

2.2.7 Strategies that were employed to enhance qualitative rigour and improve the quality of the study design

The interpretive strategies that were employed in this study to bolster qualitative rigour may at times resemble positivist validation and reliability measures (C.E. Hill, Chui, & Baumann, 2013; Golafshani, 2003; Stiles, 2013). However, the qualitative strategies were firmly embedded in the interpretive paradigm; and it is based on an epistemological framework that is congruent with qualitative inquiry (Edwards et al., 2004; Elliot, Fischer, & Rennie, 1999; C.E. Hill et al., 2013; Stiles, 2013).

Table 4 describes the underlying rationale of different qualitative strategies to enhance rigour; the application of these strategies in this study is also explained.

Table 4:

Strategies that were Used to Enhance the Qualitative Rigour of this Study

Qualitative Strategy	Rationale of strategy	Application of recommendations or guidelines in the present study
Improving credibility through "narrative knowing"	<p>The strategy involves the inclusion of detailed narratives to enhance the credibility of each case study (McLeod, 2012).</p> <p>Credibility is achieved when the content of the narrative resonates with the reader's own theoretical knowledge and clinical experiences (Edwards et al., 2004; McLeod, 2012; Simons, 2009).</p>	<p>All the psychotherapy sessions were transcribed and captured in narrative format. The narrative descriptions of sessions within each case study are presented in Chapter 3.</p>
Improving credibility by having external examiners to check thematic coherence	<p>Credibility also refers to the veracity of research which implies that the primary data should be reflected in a truthful and believable manner (Elliot et al., 1999; Luck et al., 2007).</p>	<p>Each case study included a comprehensive case conceptualisation, a description of therapeutic process and reports that covered the outcome of intervention.</p> <p>The primary research material, e.g., transcripts, audio-recordings and written notes were made available to two experienced psychotherapists within the ID field.</p> <p>The two clinicians engaged in a recursive process to establish whether thematic analysis corresponded with the data material of each case in a coherent and credible manner.</p> <p>The one clinician</p>

<p>The use of peer supervision to enhance credibility</p>	<p>External credibility is enhanced if peer supervision is used to facilitate researcher reflexivity (Hollway, 2014). This allows the researcher to become increasingly aware and sensitive to the role of his personal opinions and possible bias when analysing research (Hollway, 2014; Hollway & Jefferson, 2013).</p>	<p>independently analysed the first and last case study before perusing the transcripts, notes and audio-recordings. In both cases she identified themes that by and large converged with the themes I identified. A more detailed account of this process is provided in Appendix A.</p> <p>I engaged in peer supervision with a qualified psychotherapist and clinical psychologist with experience in the ID field. Supervision amounted to more than 14 hours in total.</p>
<p>Procedural uniformity across cases</p>	<p>Psychometric test procedures and the method of analysis should be uniform across different case studies (McLeod, 2012).</p>	<p>A detailed account of the supervision process and the content that was discussed is included in Appendix A.</p> <p>With the exception of the BDI-II, the same battery of tests was used across five of the six case studies.</p>
<p>Enabling transferability/generalisability between cases</p>	<p>The qualitative strategies that are used to enhance transferability could be compared with measures to optimise external validity in qualitative research (Padmanabhanunni, 2010):</p> <p>Qualitative case study research explores divergent and convergent</p>	<p>Thematic analysis was used to interpret the research material within and between the six cases.</p> <p>The thematic analysis within each case represented the first step of analysis. Generalizability or transferability was achieved when themes from one case study were replicated in</p>

	<p>themes <i>within</i> individual responses. In turn, the different responses of each case study may have broader applicability to allow generalisation towards similar theme-related content in other cases (Eells, 2007; Elliot et al., 1999; Guba & Lincoln, 1994; Lincoln & Guba, 1985; McLeod & Elliott, 2011; Shean, 2012; Silverman, 2013).</p> <p>Generalisation occurs when the findings of a new case are collated with convergent themes or clinical similarities in other cases, i.e., "replication on a case to case base" (Hilliard, 1993, as cited in Edwards et al., 2004, p. 592). The replication of similar thematic content across individual cases could culminate in "case law", i.e., established similarities between "different operationalised phenomena" (Edwards et al., 2004, p. 592).</p>	<p>subsequent case studies.</p> <p>I therefore identified a number of themes that emerged from the respective cases, and transferability was achieved after I had described the findings of salient thematic content across different cases in Chapters 4 and 5.</p>
Improving dependability	<p>In quantitative research, reliability measures are used to establish if research is replicable: high reliability attests to a high quality of research (Golafshani, 2003; McLeod, 2012).</p> <p>In qualitative research, dependability, i.e., that the analysis is based on research material that was accurately captured and presented, is usually not achieved by means of statistical aggregation (McLeod, 2012).</p> <p>A third party assessor could assess the accuracy of written transcripts when they are compared against audio or video recordings (Edwards et al., 2004).</p> <p>Furthermore, third party assessment has the potential to establish whether information was <i>presented</i> in a systematic, logical and coherent</p>	<p>The research material was made available to a third party assessor to establish the accuracy of audio recordings. The accuracy of written transcripts was accomplished by the quantification of omissions and additions in a randomly selected session of each case.</p> <p>As described earlier, two other clinicians with experience in ID clinical psychology also had access to the research material and thesis draft. They assessed the readability and general flow of information</p>

	<p>manner.</p> <p>Lines of arguments that lead to eventual conclusions also need to be clear and coherent through different levels of analysis, i.e., without inexplicable leaps that leave the reader unsure on what grounds conclusions were drawn (Edwards, 2010a, 2010b; Golafshani, 2003; Padmanabhanunni, 2010).</p>	<p>across the data set. They also critically evaluated my thematic analysis and conceptualisations of each case study.</p>
Laying the foundation for future confirmability	<p>Confirmability relates directly to the way in which a study's findings could be confirmed by other studies that will use similar qualitative research strategies (Edwards, 2010b; Guba & Lincoln, 1994; Silverman, 2013).</p>	<p>In the context of the current study, other single case studies that focus on the maternal experiences of mothers of adults who have ID and behavioural difficulties will extend the <i>confirmability</i> of findings.</p>

These measures to enhance qualitative rigour in psychotherapy research had been employed successfully in other South African studies that were conducted in low-resourced settings (e.g., Padmanabhanunni, 2010).

2.2.8 The adoption of action research to ground the exploratory agenda of case-based research

Although the study used a mixed methods design and a series of single psychotherapy cases, the complexity of individual factors and role of adverse social circumstances and service delivery constraints led to the adoption of a broader research agenda.

As the primary investigator, I am employed as a clinical psychologist and psychotherapist in the real world clinical setting where research was conducted

(McLeod, 2012; Robson, 2011). The clinic provided services for adults who have ID and psychiatric disorder and/or behavioural difficulties including aggression.

We depended on parents to provide full-time care for their children; and to accompany their children to appointments; and to ensure that our service users comply with pharmacological treatment. I also relied on parents to assist with homework assignments when conducting cognitive-behavioural intervention with their children. In fact, with the advancement of low arousal approaches to manage aggressive behaviour, the capacity of caregivers to deal with behavioural difficulties has received attention; and the reciprocity of mutual arousal of parent and child during adverse incidents is now increasingly acknowledged (McDonnell, 2010).

While the present study had not formally adopted participatory action research to inform data collection (Robson, 2011), interviews scheduled before and after the completion of psychotherapy intervention explored maternal perceptions and the mothers' experiences of the research process. The interview findings were integrated with the thematic analysis of sessions. Participants therefore played an active role in the data collection process. In this regard, the interactive and dynamic process of case study research lent itself to the epistemological emphasis of action research on participatory experiences in a clinical setting (McLeod, 2012; Robson, 2011).

2.3 Characteristics of Participants

2.3.1 Number of participants

As described earlier, the study consisted of six single cases that were aligned in a series of case studies. In qualitative research, saturation is achieved when the groups and codes from the most recent data mostly correspond with the codes and themes that were generated in earlier data collection initiatives. New groups or codes with novel themes are therefore not revealed by the data that were more recently collected (McLeod, 2012). In the current study, saturation was achieved in the sixth case study.

2.3.2 Location of research

This study took place in the Out-Patient Department of Alexandra Hospital, a public hospital for adults who have ID in the Western Cape. The Out-Patient Department (OPD) provided multidisciplinary services for community-based adults who have ID and co-morbid psychiatric diagnoses and/or marked behavioural difficulties. The multidisciplinary team comprised a psychiatrist, two clinical psychologists, a social worker, OT and a nurse with advanced psychiatry training. At the time of the research, to the best of my knowledge, Alexandra's OPD Department was the only specialised unit in Africa that focused exclusively on the provision of services for adults who have ID, psychiatric disorder and complex behavioural support needs.

2.3.3 The recruitment process, inclusion and exclusion criteria

i) Inclusion criteria

The six mothers were recruited from OPD whilst they accompanied their children to clinical appointments at the clinic. Although a convenience sample was used, I was mindful of Cape Town's cosmopolitan demographics and tried to recruit a small sample of participants that represented different language and cultural groups. Three of the participants were English-speaking and three were Afrikaans-speaking. Two participants were white, one was Indian and the remaining three participants were coloured. Potential participants were recruited in the following manner:

- I informed members of the multidisciplinary team about the undertaking to conduct individual psychotherapy with mothers of adults who have ID and aggression. Clinicians agreed to refer potential participants once they had observed high levels of parental stress. In such instances, the clinician obtained the potential participant's permission that allowed me to make contact with them.
- A similar procedure was followed in the Acute Psychiatric Units for community-based men and women who had ID and psychiatric disorder and/or behavioural difficulties: I attended clinical ward rounds and the names of parents were identified through discussion of their children's behavioural difficulties.
- Without assuming that the child's high behavioural support needs would have necessarily translated into heightened levels of parental stress, I made telephonic contact with potential participants or they were directly approached when accompanying their children to the OPD clinic.

If the potential participant was willing to participate in the study, a screening interview was arranged to cover the following:

- Confirmation that the potential candidate is the primary caregiver.
- Confirmation that the child was previously diagnosed with an intellectual disability by a psychologist with the use of standardised psychometric tests.
- I also asked probing questions to ascertain whether the following inclusion criteria were met:
 - The presence of high levels of parental stress.
 - Reported difficulty in coping with the child's aggression.
 - I also established whether the frequency, severity and duration of the child's aggression met the DC-LD criteria of aggressive behaviour (Royal College of Psychiatry, 2001).
 - Following parental consent, I obtained information from the child's hospital folder to confirm aggression and a diagnosis of ID.

ii) Exclusion criteria

Participants were not considered if one or more of the following was present:

- The child lived in a community-based group home or residential setting.
- Non-fluency in English because of psychometric requirements; all the tests were in English.

2.3.4 Vulnerability and informed consent: parent and child

Ethical approval for this study was sought and granted by the Human Resource Ethics Committee of the Faculty of Health Sciences at the University of Cape Town.

The children of participants were at times required to visit the hospital with their mothers when their parents attended psychotherapy sessions. I therefore provided participating mothers and their children with the option of having their child supervised whilst she was attending therapy.

Information-processing deficits confound the process of obtaining consent among persons who have ID (Cameron & Murphy, 2006). However, because the study also implied discussion of the child's behavioural difficulties in a psychotherapeutic relationship with participating mothers, there was an ethical and moral obligation to try and obtain consent from their children (Capri & Coetzee, 2012).

2.4 Recruitment, Enrolment and Informed Consent from Parents and their Children

Following confirmation that the potential participant met the inclusion criteria of the study, the screening interview proceeded in my office, which was in another part of the OPD building and away from the area in which clinical work was conducted:

- The study's rationale was disclosed in concrete terms. Research was described as a form of individual psychotherapy that would be provided to distressed mothers of adults who have ID and aggression. The research venue was disclosed. The concepts of parental stress and negative maternal emotions were explained without reverting to psychological jargon. I also reiterated and explained the voluntary nature of participation, and that the

participants were free to withdraw at any stage of research without the need to provide an explanation of their decision to discontinue participation.

- I quantified the duration of research by describing the process as comprising 10 - 12 consecutive weeks of intervention that would on average not exceed two hours per week. This allowed for pre and post assessment and an expected number of six therapy sessions per participant.
- I reiterated that research did not incur any cost to participants; I also disclosed that transport money was available within reasonable limits.
- Separate interviews with mother and child were held once the mother showed an interest to participate in the research project. I first ensured that the child was comfortable with the supervision arrangements before I proceeded with the interview to obtain consent from his mother.
- I provided the parent with the *"Consent to Participate in the Research Project"*-form. The form contains the rationale and all the practical details with regard to attendance, cost, travel reimbursement, and the possible supervision opportunities at the clinic for her child while she was attending psychotherapy and other research activities.

I tried to answer questions as honestly and comprehensively as possible. The potential participant was also informed about potential risks and benefits.

- Potential participants were given the opportunity to discuss the implications of regular attendance with family and relatives before making a final decision. With the exception of one participant, all of the mothers provided informed consent in written form on the day of the screening interview.

- The next step involved an interview with the participating mother's child to obtain informed consent in cases when the child had mild or moderate ID. Five of the participants had children with mild ID; and the second case study involved a mother whose daughter had moderate ID.
- I explained the rationale of research, including the advantages and disadvantages of participation, with the use of a separate form, the *Child Consent Form*.
- I used the clinical skills that I have acquired over the years as a psychologist and psychotherapist working with children and adults who have ID. Hence, the interview was aligned with clinical observations of the person's communication abilities, information processing strengths, and propensity to acquiesce.

Language was simplified and instructions repeated; technical jargon and the overuse of the passive form of language were also avoided. As evident in Appendix 3, the document itself used pictorial and visual material to augment verbal communication (Whitehouse, et al., 2006).

The children were all able to follow instructions and, depending on their ability to write, they provided verbal or written informed consent about the research process. They were also willing to accompany their mothers to sessions, although this was seldom necessary since most of the mothers preferred to make other arrangements for supervision whilst participating in the research project.

2.5 Research Procedures and Data Collection

Table 5

Summary of Psychometric Tests Used in the Study

Psychometric Instrument	Author	Date of publication	Approximate administration time
Caregiver Protocol			
Socio-Economic Questionnaire	n/a	n/a	10 minutes
Hope Scale	Snyder et al.	1991	5 minutes
Parental Locus of Control Scale	Campis, Lyman, & Prentice-Dunn	1986	15 minutes
Parenting Sense of Competence Scale	Gibaud-Wallaston & Wanderman	1978	5 minutes
Parenting Stress Index – Short Form	Abidin	1995	10 minutes
Ways of Coping Questionnaire – Revised	Folkman & Lazarus	1988	15 minutes
TOTAL ADMINISTRATION TIME	60 minutes		

2.5.1 Use of psychometric tests in the South African context

None of the psychometric tests that form part of the protocol had been standardised on the South African population. As described earlier in the chapter, psychometric results were not used to obtain aggregate quantification across cases, but rather to gauge each person's progress at different intervals of intervention. The focus was on intra-subject-variation, i.e., the use of psychometric tests to trace a participant's response to therapeutic input *within* each case.

The first case was used as a pilot case study to gain experience in the administration of the battery of tests.

2.5.2 Qualifications of researcher

Psychometric assessment and CBT intervention were conducted by the same researcher, a qualified and registered clinical psychologist and psychotherapist at the Health Professions Council of South Africa. At the time of completing the thesis, I had more than 14 years of experience in the field of intellectual disability. CBT training formed part of my post-graduate training in clinical psychology; and I was supervised in the use of CBT after graduation. I also have experience in the administration, scoring and interpretation of psychometric instruments.

As primary investigator, the extensive input and support from the project's supervisors were central and incisive during the data collection process and thematic analysis. Both supervisors are seasoned researchers and experts in their respective fields.

2.5.3 The protocol of psychometric tests employed in research

2.5.3.1 The Hope Scale (HS; Snyder et al., 1991)

The Hope Scale consists of 12 items and takes approximately 5 minutes to complete. Permission to use the instrument was obtained from the American Psychiatric Association. The instrument distinguishes between two additive and interrelated concepts, *Agency* and *Pathways*. Internal consistency as measured by Cronbach's alpha ranges between 0.71 and 0.76 for the Agency subscale and 0.63 to 0.80 for the Pathways subscale (Lloyd & Hastings, 2009; Snyder et al., 1991). Agency refers to an individual's subjective determination to realise past, present and future goals. Pathways describe the ability to conceptualise alternative plans or ways to attain goals. According to Snyder et al. (1991), hope has an enduring quality that is characterised by cognitive appraisals about individual goal-directed

abilities. The cognitive component measured by the HS relates to the study's use of cognitive-behaviour therapy.

Snyder et al. (1996) proposed that hope can be measured at a dispositional (trait) level or a situational (state) level. This study measured hope as a dispositional trait, which implies a consistent state with little variation over time. The decision to measure dispositional hope was based on the observation that caregiving persists through the course of decades. The implied chronicity could therefore result in prevailing views of parenting that have an enduring quality.

Lloyd and Hastings (2009) have found that very few studies have explored hope among parents of children and adults who have ID. The authors successfully used the HS with parents of children who have ID. Reported Cronbach's alpha coefficients ranged between 0.69 to 0.80.

2.5.3.2 Parental Locus of Control Scale (PLOC; Campis et al., 1986)

Campis and his colleagues (1986) based the development of the PLOC scale on previous studies that have found associations between parental locus of control and communication patterns between parent and child, the development of the child's locus of control, parent-child interactions, and parental perceptions about their children. The last two aspects are especially relevant to the current study, in view of the confirmed relationship between parenting stress and parental cognitions about the behavioural difficulties of the child (Hassall et al., 2005).

The PLOC consists of 5 subscales:

- Parental Efficacy subscale
- Parental Responsibility subscale

- Child Control subscale
- Fate/Chance subscale
- Parental Control subscale

The PLOC also has a total scale; and higher attainments on this instrument suggest the presence of an external parental locus of control. The PLOC has 47 items and takes approximately 15 minutes to administer.

I obtained permission to use the instrument from one of the authors. Internal consistency as measured by Alpha coefficients for the five subscales range between 0.65-0.77 and 0.92 for the total scale. The instrument has good construct and discriminant validity (Campis et al., 1986; Hassall et al., 2005). Two recent studies, Hassall et al. (2005) and C. Hill and Rose (2009), have successfully used the PLOC to examine locus of control in parents of adults who have ID.

2.5.3.3 Parenting Sense of Competence Scale (PSOC; Gibaud-Wallaston & Wandersman 1978, as cited in Johnston & Mash, 1989)

The PSOC, originally developed by Gibaud-Wallaston and Wanderman (1978), consists of 17 items that are graded on a 6-point Likert scale ranging from *Strongly Disagree* to *Strongly Agree*. The instrument is not published but available in the public domain as is evident by its use in many studies. Efforts to contact the authors were unsuccessful. Subsequent enquiries to researchers who have used the instrument have indicated that the instrument remains available in the public domain 30 years after its publication.

Johnston and Mash (1989) examined the factor structure of the PSOC and identified two factors, *Efficacy* and *Satisfaction*. *Satisfaction* describes an affective component of parenting and refers to parental feelings of frustration, anxiety and general

motivation. *Efficacy* measures self-efficacy and reflects to what extent parents feel “competent and confident in handling child problems” (Johnston & Mash, 1989, p. 167). Alpha coefficients of 0.79 for the entire score, 0.75 for the Satisfaction factor and 0.76 for the Efficacy factor were reported (Gilmore & Cuskelly, 2008; Johnston & Mash, 1989).

A literature review of parenting self-efficacy identified the PLOC as the most frequently used scale to measure the domain of parenting self-efficacy (Jones & Prinz, 2005). Relevant to the proposed study, the PSOC has been used in previous studies that have investigated parental experiences among parents of children who have Down syndrome and autism (Belchic, 1996), stress and coping of mothers of children who have pervasive developmental disorders (Tobing, 2005) and cognitive variables of parents of children (Hassall et al., 2005) and adults (C. Hill & Rose, 2009) who have ID.

The PSOC has also been used as an instrument to measure parental self-efficacy among parents whose children have other clinical conditions such as ADHD (e.g., Lehner-Dua, 2002) and phobia (Bowers, 2002). Last, the use of the PSOC extends to studies which have focused on parental self-efficacy in parents who have substance abuse problems (Laughinghouse, 2010).

2.5.3.4 Parenting Stress Index – Short Form (PSI-SF; Abidin, 1995)

The Parenting Stress Index (PSI) is frequently used as a reliable instrument to measure parental stress. Because the PSI is lengthy to administer, Abidin (1995) developed a shorter 36-item questionnaire that is based on factor analysis of the PSI.

Three domains were developed as subscales of the PSI-SF: *Parenting Stress*, *Parent-Child Dysfunctional Interaction* and *Difficult Child*. It also provides a total stress score (Haskett, Ahern, Ward, & Allaire, 2006). The PSI-SF takes approximately 10 minutes to administer (Abidin, 1995). The PSI-SF was purchased from Psychological Assessment Resources and permission to use the PSI-SF followed legitimate procurement.

The three subscales can be summarised as follows:

- *Parental Distress* results from the individual characteristics of parent and child (Abidin, 1995).
- *Parent-Child Dysfunctional Interaction* measures negative perceptions about the child, e.g., parental conceptions that the child is abusive, rejecting or a disappointment to parental aspirations.
- *Difficult Child* describes behaviour that might make effective caregiving and management of the child more difficult.

The PSI-SF has been extensively used across various clinical populations, e.g., parents of low SEP (Reitman, Currier, & Stickle, 2002), parents of children who suffered from traumatic brain injury (Hawley, Ward, Magney, & Long, 2003), a comparison between parents of children who were diagnosed with cancer and parents of children who have physical disabilities (Wen Hung, Wu, & Yeh, 2004), parents of children who have Asperger syndrome (Kroodsma, 2008), and mothers of children who have psychiatric disorders (Kearney, 2008).

The PSI-SF has also been used to assess parental stress among mothers and fathers of children who have DD (e.g., Hassall et al., 2005). Mori, Ujiie, Smith, and Howlin (2009) conducted a comparative study to measure levels of parental stress

between parents of children who have autism and those whose children were diagnosed with Asperger syndrome. In another recent study, parenting stress was measured among parents of children who have Cornelia de Lange syndrome and Down syndrome (Richman et al., 2009).

Cronbach Alpha scores estimate an internal reliability subscale range of between 0.80 – 0.91 (Abidin, 1995). It should also be noted that the correlation between total scores on the long and short form of the PSI-SF is rather high (0.87) (Haskett et al., 2006).

2.5.3.5 Ways of Coping Questionnaire - Revised (WAYS; Folkman & Lazarus, 1988)

The Ways of Coping Questionnaire - Revised measures the thoughts and actions that are used by persons to cope with stressful situations.

Folkman and Lazarus (1988) argued that the distinction between problem-focused and emotion-focused coping fails to recognise that some forms of coping are underpinned by both, e.g., seeking advice could be used as part of a problem-focused approach or a form of emotional support. The authors therefore developed eight empirically-derived coping scales that are broadly representative of ways in which adults cope with stressful situations:

- *Confrontive Coping* describes an individual's confrontational intention to change the stressful event. Confrontive coping may include elements of antagonism.
- *Distancing* is defined by Folkman and Lazarus (1988, p. 7) as "cognitive efforts to detach oneself and to minimize the significance of the situation".
- *Self-Controlling* refers to a person's attempts to control emotions and behaviour.

- *Seeking Social Support* refers to efforts to obtain knowledge and to seek assistance and support from others.
- *Accepting Responsibility* implies that an individual accept responsibility for their contribution to a stressful event; and to attempt restitution of some form.
- *Escape-Avoidance*: According to Folkman and Lazarus (1988, p. 7), the scale describes “wishful thinking and behavioural efforts to escape or avoid the problem.” The scale is on the opposite end of the Distancing scale.
- *Planful Problem Solving* is defined by Folkman and Lazarus (1988, p. 7) as "deliberate problem-focused efforts to alter the situation, coupled with an analytic approach to solving".
- *Positive Reappraisal* takes place when a person attempts to find new meaning in stressful situations by perceiving such events as opportunities for self-advancement.

Developed for use in the adult population, the Ways of Coping Questionnaire - Revised consists of 66 questions and takes approximately 10 minutes to administer (Folkman & Lazarus, 1988). The WAYS was purchased from Mindgarden Inc. Permission to use the WAYS has followed legitimate procurement. Internal consistency on the WAYS measures in the acceptable range with alpha coefficients of between .66 and .79 (Folkman & Lazarus, 1988).

The WAYS has been used in various studies to describe the coping strategies of parents who have children who have autism (Pisula & Kossakowska, 2010), parents of children who have DD (Glidden et al., 2006), and genetic disorders commonly associated with ID, e.g., Down syndrome (Hatton, Knussen, Sloper, & Turner, 1995). Knussen, Sloper, Cunningham, and Turner (1992) administered the WAYS on parents of children who have Down syndrome and found adequate internal reliability,

acceptability and validity. The authors concluded that the instrument is potentially valuable in studying patterns of coping in families and caregivers of people with complicated care needs including persons who have ID.

2.5.3.6 The Beck Depression Inventory II (BDI-II; Beck, Steer, & Brown, 1996)

The Beck Depression Inventory II is a 21-item questionnaire that measures the severity of depression among adults and adolescents (Beck, Steer, & Brown, 1996).

It takes on average less than five minutes to complete. The BDI-II provides a total score of depression that is subdivided into the following categories of severity:

- 0-13 minimal depression
- 14-19 mild depression
- 20-28 moderate depression
- 29-63 severe depression

(Beck et al., 1996)

One study has found an internal consistency of 0.91 in a sample of university students (Dozois, Dobson, & Ahnberg, 1998). Another study has found coefficient alphas of 0.91 among community-based mental-health service users (Beck, Steer, Ball, & Ranieri, 1996).

The BDI-II was introduced as a clinical instrument in the second case study after I had observed clinical depression in the first case study. The BDI-II also assisted with treatment planning. In four of the remaining case studies, participating parents completed the BDI-II before the onset of each session. This enabled us to track therapeutic progress (or the lack thereof) across all the sessions.

2.5.4 Design of cognitive-behavioural intervention

Each case consisted of six to 13 sessions. The first session of each case study was used to obtain a full personal history and more information about the presenting problems, distressing aspects of the child's behaviour, and aspects of other negative and positive psychological states.

In accordance with the suggested format that was laid out by J. S. Beck (1995), the first session was also used to socialise the participating mother to CBT. J. S. Beck's (1995) format and structure of sessions are presented below:

- Intake interview and first session:
 - Full psychiatric interview in order to plan CBT treatment.
 - Agenda setting.
 - Symptom checks.
 - Discussion of the presenting problems.
 - The formation of therapeutic goals of intervention.
 - A didactic approach to provide the participating parent with knowledge and information about their psychological problems.
 - To obtain information about the participant's ideas and expectancies of psychotherapy.
 - Relaying the rationale of homework and discussion of the first homework assignments.
 - A summary of the session and request that the participant provides feedback.
- Session two onwards:
 - An update of the week's events and symptom checks.
 - Bridging from the previous session.

- Setting the agenda for the session in a collaborative manner.
- We also allocated time to go through the homework that the participant had to complete from the last session; and agree on a new homework assignment.
- Working through the agenda items that were identified.
- At the end of the session, a summary of the session was provided, and the participant was requested to provide feedback about her experience of the session.

2.5.5 Semi-structured interviews before and after completing psychotherapy

Semi-structured interviews are widely used in qualitative psychological research (Brinkmann, Jacobsen, & Kristiansen, 2014). Semi-structured interviews consist of a limited number of open-ended questions that elicit specific phenomena and experiences from the perspective of the participant. Some of the questions may have prompts to assist the respondent, especially when the question is based on particular theoretical underpinnings or when participants find it difficult to conceptualise their unique perspectives (Brinkmann et al., 2014; Wilkinson, Joffe, & Yardley, 2004).

When compared with structured and unstructured interviews, semi-structured interviews have the following advantages:

- The interviewer has more opportunity to engage in the process of knowledge-generation in a co-constructed space that is shared by the researcher and participant (Brinkmann et al., 2014). As opposed to structured interviews, the researcher is able to deviate from the set of questions to hone in on responses that contain tangible emotional content (Wilkinson et al., 2004).

- Unlike unstructured interviews, semi-structured interviews allow the researcher to focus the interview on specific areas of investigation that are relevant to the research project (Brinkmann et al., 2014; Wilkinson et al., 2004).

Wilkinson and her colleagues (2004) have described a set of skills that researchers require to conduct interviews:

- The interviewer should have active listening skills, be aware of his non-verbal responses, and have a generally quiet presence in the room to allow interviewees to formulate their answers in a coherent fashion.
- Displays of empathy would facilitate honest and authentic responses. Care should be taken to avoid a judgmental attitude.
- An interviewer should be able to paraphrase and reflect the participants' train of thought in a precise manner, thereby avoiding the possibility of imposing his own ideas onto the interviewee.
- Interviews should capture feelings and thoughts; the presence of strong emotions often signifies ambiguous or socially-sensitive beliefs. A skilled interviewer should facilitate the interviewing process in a manner that allows the participant to explore difficult emotions.

In each case study, semi-structured interviews were held before the onset of psychotherapy as well as after psychotherapy had been completed. The questions of pre- and post-interviews are presented below.

- ***Interview Schedule: participant's experience of parenting stress, the parent-child relationship, coping and expectations of psychotherapy***

A) Becoming aware of your child's intellectual disability

- 1) When did you first become aware that your child is intellectually disabled?
- 2) Looking back to the time you found out – how did you deal with the news?

Prompts: thoughts, feelings – adjustment or coming to grips with by implementing change.

- 3) As your child grew older, how did caring for a disabled child change your life?

Prompts: Work, family life, relationships.

B) Coming to grips with the child's psychiatric illness or behavioural problems

- 4) What went through your mind when your child's behavioural problems or psychiatric illness started?
- 5) How did you go about seeking help?

Prompts: Accessing formal support – school, clinic, hospitals.

- 6) Describe your experience of the help you've received since your child's behavioural problems started?
- 7) Describe support (if any) from family and friends. What value do you attach to it?
- 8) What is the best advice anyone has given you to deal with your child's aggression?

- 9) What is the worst advice anyone has given you to deal with your child's aggression?

C) Mothers' experience of parenting stress

- 10) Why do you experience your child's behavioural problems as stressful?
- 11) Are you more stressed at certain times than others? If so, why?
- 12) Regarding your child's aggression, what are your worst fears for yourself and your child?

D) The parent-child relationship

- 13) Tell me more about the relationship between you and your child.

Prompts: impact of aggression on relationship, parental views of child and how this permeates their relationship, positive aspects of relationship.

- 14) Describe your typical day and the different tasks and responsibilities you take on as part of looking after your child?

E) Coping with caregiving challenges and parenting stress

- 15) When caregiving makes you feel stressed or tired, what do you generally do to feel better?
- 16) What are the most difficult and stressful caregiving tasks?
- 17) How do you manage your child's aggression on a day to day basis?
- 18) Explain why you believe these strategies to be effective or ineffective.

F) Hope and expectations of psychotherapy

- 19) What are your thoughts and feelings about the future for yourself and your child?
- 20) What did you have to give up since you've become the caregiver of your disabled child?
- 21) What are your expectations of therapy?
- 22) Did your role as mother of a disabled child change your perceptions about life and the meaning of life?
- 23) Did your role as mother of a disabled child change your perceptions about yourself? If so, how?

Interview schedule: Exit interview - Participants' experience of the therapeutic process

- 1. Could you describe your experience of the whole process of interviews, tests and therapy?
- 2. In your own words, please describe your experience of therapy.
- 3. Having gone through the process of therapy, what is your understanding of the role of thoughts when facing a problem?
- 4. How would you relate these thoughts to the stresses you have of your child?
- 5. Did therapy change anything in the way you view yourself? If so, please explain.

6. Did therapy change anything in the way you view yourself as parent? If so, please explain.
7. Did therapy change anything in the way you view your child? If so, please explain.
8. What is your understanding of coping?
9. Did therapy help you to cope better? If so, please tell me more.
10. Describe how you've experienced self-help assignments and practical work.
11. What did you find most useful about the therapy?
12. What did you find least useful?
13. What recommendations would you have for future research in this area?

The rationale behind the pre-intervention interviews was to elicit maternal perceptions regarding some of their earlier caregiving experiences. I also based some of the questions on findings from relevant intellectual disability research. For example, parents of children and adults who have ID often cited inadequate social support as a major stressor (e.g., Hayes & Watson, 2013). Question 7 dealt specifically with the availability of support from family and other acquaintances.

The first interviews were particularly helpful in the case conceptualisation of each participant. Many of their responses were directly incorporated with conceptualisations that covered the predisposing, precipitating and maintaining factors of each case study.

The last interview of each case study focused on each participant's experience of therapy. I conducted the interviews with participants. My role as therapist and

interviewer could be legitimately questioned and remained one of the main weaknesses of this study. Moreover, an argument against the credibility of the post-interviews would cast doubt on whether participants felt open to criticise therapy and highlight the potential negative aspects of therapy if the interviews were conducted by myself as the therapist.

As was the case with the psychometric tests, we did not have the fiscal and human resources to employ another researcher to conduct individual interviews at different intervals of the research process. However, in hindsight I thought it would have been more useful if another researcher had conducted a joint interview with all the participants after all the case studies were completed.

2.6 Data Safety and Monitoring Plan

All the data that were collected in this study were stored in a locked office. I also saved all the electronic data, e.g., written transcripts and audio-recordings, on a personal computer that was password-protected and secure.

2.7 Data Reduction and the Analysis of Data

2.7.1 The process of data reduction in the study

The study design of each case is described in Figure 3. The entire set of data or research material consisted of the following:

- Consent and assent forms that were obtained from participants and, when possible, their children.
- Psychometric assessment.
- Psychotherapy process notes and written or electronic correspondence between myself and the participants.

- Audio sessions of individual interviews that were conducted before and after the psychotherapy process.
- Audio recordings of each psychotherapy session of all the case studies.
- Written transcripts of interviews and psychotherapy sessions.
- Written correspondence with my supervisors.
- The thematic analysis comprising excerpts and coding.

Thematic analysis involves a form of qualitative inquiry that is recursive and iterative (Braun & Clarke, 2006; Clarke & Braun, 2013). By moving back and forth through different research documents, thematic analysis does not draw a rigid distinction between the processes of data reduction and data analysis (Braun & Clarke, 2006; Clarke & Braun, 2013; Joffe & Yardley, 2004; McLeod, 2011).

Thousands of pages of research material were generated through written transcripts of sessions, psychometric tests, notes, email correspondence and interviews. In a series of single cases, each case was thematically analysed on its own to generate codes and themes (Edwards et al., 2004). For analysis to proceed in a meaningful manner, a necessary process of data reduction had to be repeated in each case:

2.7.1.1 The first level of data reduction

In each case, the first level of data reduction consisted of a concise descriptive summary of applicable background information that contained details about the participant's life history, family functioning, psychological problems and protective factors. I also included the person's presenting complaints and occupational functioning.

Thematic analysis focused on two sources of research material during the first level of data reduction:

- The interviews that were held before the onset of psychotherapy with each participant.
- The first session of psychotherapy. The first session adhered to recommended cognitive-behavioural guidelines of the structure that should be followed at the onset of the psychotherapy process. It was based on standard psychiatric assessment schedules that facilitate comprehensive assessment of relevant intrapersonal, interpersonal and contextual information that contributed to parenting stress and the overall psychological well-being of the participant (A. Beck & Alford, 2009; J. S. Beck, 1995; Wright et al., 2006).

2.7.1.2 The second level of data reduction

The second level of data reduction led to the compilation of case formulations that covered the predisposing, precipitating and maintaining factors of each case. These factors generally accounted for the contemporary psychological problems that the participant had experienced at the time of psychotherapy (Dattilio, 2006).

2.7.1.3 The third level of data reduction

Narratives of each session were written up during the third level of data reduction and presented in Chapter Three. McLeod (2011, 2012) argues that a narrative account of psychotherapy process is fundamental to all forms of case study research.

As described earlier, extensive narratives were written to achieve a form of credibility that is associated with the process of reading: credibility is achieved if narratives resonate and hold true in line with the experiential base and knowledge of the reader (Dattilio, 2006; McLeod, 2011, 2012).

2.7.2 Strategies that were employed to analyse the third level of data

Without claiming that an exhaustive list of available literature was examined and studied because of the sheer volume of family research in the field of ID, I read up extensively on studies that have examined parental stress, maternal depression and other parental experiences among mothers and fathers of children and adults who have ID. Many of these studies were included in Chapter One.

I also brought some ideas to the research project that were based on the work that I had done with families of children and adults who have ID.

McLeod (2012) has recommended that psychotherapy case study research employs a selection or combination of the following questions to analyse research material:

- Outcome questions focus on the effectiveness and outcomes of psychotherapy within a specific case.
- Theory-building questions relate to psychotherapy process, which in turn confirms or expands existing theoretical knowledge in a specific area of psychotherapy research.
- Pragmatic-questions focus on the selection of psychotherapy methods that were used within a specific case. Other clinicians could potentially adopt similar methods if the usefulness of the employed methods is effectively demonstrated.
- Narrative questions explore therapy experience, i.e., how therapy was experienced by its constituent participants, from the perspective of either the therapist or client (p. 21).

I was mindful of the abovementioned questions when I did the thematic analysis of each case. While the emphasis was on therapeutic process from the vantage point

of the researcher-clinician; I also used narrative, pragmatic and outcome-questions in the study.

2.7.3 The analysis of data in each case study: A recursive, iterative and reflexive process

Braun and Clarke's (2006) six phases of thematic analysis are presented in Table 5:

Table 6

Braun and Clarke's (2006) Six Phases of Thematic Analysis

Thematic analysis – phase	Procedures followed
1. Researcher familiarised himself with data	Written transcripts of audio-sessions were completed and the researcher repeatedly perused transcripts and plotted down preliminary ideas.
2. Initial codes were produced	Codes were developed across all the sessions (data set) and data of each code were compared to ensure a systematic and coherent coding process.
3. Themes emerged and were plotted down	Codes were organised into themes; all the information about potential themes were clustered together.
4. Revision of themes	A “thematic map” was generated.
5. “Defining and naming themes”	Continuous analysis of themes enhanced the details and features of respective themes within the narrative of the data set; and names were allocated for themes. Each theme was convincingly defined.
6. Write-up: report of findings was completed	Appropriate abstracts were incorporated into a written and academic report of the analysis that linked the research questions and available literature with the written account.

Note. Adapted from "Using Thematic Analysis in Psychology," by V. Braun and V. Clarke, 2006, *Qualitative Research in Psychology*, 3, p. 87. Copyright 2006 by Taylor & Francis Ltd. Adapted with permission.

Table 6 describes the number of psychotherapy sessions, interviews and psychometric assessments that were conducted in each case study.

Table 7

Number of Psychotherapy Sessions, Psychometric Assessments and Individual Interviews in Each Case Study

	Number of Psychotherapy Sessions	Number of Psychometric Assessments	Number of Individual Interviews	Duration of Interviews
Case Study 1: Patricia	13	5	2	Pre: 56 m Post: 41 m
Case Study 2: Linda	10	5	2	Pre: 32 m Post: 33 m
Case Study 3: Jeanette	7	0	2	Pre: 37 m Post: 17 m
Case Study 4: Hadil	9	4	2	Pre: 41 m Post: 44 m
Case Study 5: Marlene	6	4	2	Pre: 65 m Post: 52 m
Case Study 6: Sarah	7	4	2	Pre: 41 m Post: 42 m
TOTAL	52	22	12	8 h 35m

Apart from the psychometric assessment and other research material, the thematic analysis was conducted in the following manner:

- I transcribed 38 of the 52 sessions. The remaining sessions were transcribed for me and written documents were signed to ensure confidentiality.
- I then collated the content of written transcripts with their audio sessions to ensure that all the transcripts accurately reflected audio recordings without loss or alteration of the content and implicit meaning of the discourse during each session.
- The third party assessor listened to a randomly selected session of each case to quantify additions and omissions to ensure that accuracy was maintained through the act of transforming verbal language into a written account.

- Consistent with the underlying epistemology of qualitative research, I played an active, interpretative role in the analysis, which involved a recursive and iterative process (Braun & Clarke, 2006; McLeod, 2011). I therefore immersed myself in the process of transcription and continually read through the entire data set of written transcripts as they were completed. Initial notes were made during the transcription of the four case studies that I transcribed. The remaining two case studies were also recursively perused, to and fro, with notes of interesting content plotted down next to their demarcation on the data set.
- Each psychotherapy session was treated as a data item and the sum total of items formed the case study or unit of analysis. The analysis first attempted to produce codes and eventual themes in each case.
- The expansion of data through electronic notes, written clauses, phrases and paragraphs represented a necessary step in this qualitative component of the research project. I subsequently reduced the data into meaningful units by coding emerging content (McLeod, 2011; Yin, 2014).
 - Codes represent “. . . the most basic segment, or element, of the raw data or information that can be accessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998, in Braun & Clarke, 2006, p. 88).
- Themes were drawn from the coding process. Braun and Clarke (2006, p. 82) describe a theme as a construct that “. . . captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set”.

- I compiled a narrative of each session that captured the psychotherapy process of each session. Although every narrative provided a sequential or linear account of events that occurred within the session, the analysis was also thematic because themes were selected according to their relevance to the study's research question.
- The recursive process also implied that I continuously collated themes from different narratives with each other as they were written up. The write-up process was not linearly aligned as the after-product of field work. It was iteratively produced through continuous engagement with the research material (Joffe & Yardley, 2004; McLeod, 2011, 2012; McLeod & Elliott, 2011; Yin, 2014).
- Sections of the narratives were re-written and adjusted as new information came to light in subsequent sessions. The material was also reorganised and re-written from my ongoing engagement with the data and continuous reflexivity.
- In addition, with the intention of ensuring complementarity between the thematic analysis and psychometric test results that formed part of the mixed methods design of the study, results from psychometric assessment were integrated with the thematic analysis in the narrative structure. Consistencies and inconsistencies between the analysis and test results were thereby critically evaluated and incorporated (Padmanabhanunni, 2010).

2.7.4 The analysis of thematic content within each case and between cases:

The study's thematic analysis of intra-subject variation and the transferability of themes across cases

- The research material of each case was analysed to generate codes and themes *within* the case, i.e., intrasubject variation (Edwards et al., 2004; McLeod, 2011; 2012).

To ensure coherence and contiguity, I went back to the narrative descriptions of earlier cases if emerging material in subsequent cases showed similarities and overlap with the earlier cases (Edwards et al., 2004).

I then collated the themes that emerged from the narratives of each case with findings from existing literature. As part of the interpretive act, under "Discussion", some of the themes of the specific case study were discussed in terms of their relevance, overlap or deviation from existing literature.

- The second step involved the transferability of thematic content *across* cases. After the thematic analysis of each case, I described themes that were evident *across* cases as depicted in the thematic content of each case. The findings of the across-case analysis are discussed in Chapter Four. The themes that emerged from multiple cases were again collated with available literature.

In order to avoid replication because of the word count limit of the thesis, I did not discuss all the themes of each case study under the case study's "Discussion" section. Themes that were present and repeated across cases were described and discussed in Chapter Four.

CHAPTER THREE: THEMATIC ANALYSIS OF SINGLE CASES AND INTEGRATION WITH TEST RESULTS

3.1 The first case study: Patricia*

3.1.1 Introduction

At the time of intervention, Patricia was a fifty-two-year-old married woman with three children. Her daughter, thirty-five-year-old Sue, was diagnosed with mild ID and poorly-controlled nocturnal epilepsy with post-ictal psychosis. A psychiatrist also queried whether Sue was on the autistic spectrum, although formal observational schedules such as the Autistic Diagnostic Interview were not administered to confirm the diagnosis.

Sue presented with frequent episodes of verbal aggression, intermittent physical aggression and property destruction. She also displayed demanding and re-assurance seeking behaviour when her requests were not immediately met. On Sue's referral to clinical psychology, Patricia reported to another clinician that she had been unable to manage her daughter's behaviour for many years. She also described Sue's behaviour as getting worse: episodes occurred more frequently and were becoming progressively more severe. As a result, she found it increasingly difficult to cope with caregiving demands. When Patricia confirmed that she was continuously feeling stressed and worried, she was referred to me, and I subsequently invited her to participate in the research initiative.

Patricia married young and had three children. Sue's epilepsy developed during infancy. At the time she had more than a hundred absence seizures a day as well as two or more nocturnal seizures in the form of generalised tonic-clonic convulsions. Patricia used to have Sue's mattress in their bedroom to "keep an eye"

* Fictional names were used in all the case studies.

on her. She vividly recalled some of her experiences when she had woken up in the middle of the night, hearing her daughter's muted banging against the floor whilst the tonic-clonic convulsion took its course. Patricia remembered being completely helpless to prevent such convulsions. She also recalled her worry and panic at the time, fearing that Sue might die.

At the earlier times of parenting, Patricia stated that she had received minimal support from her husband, who battled with alcohol dependence and pronounced binge drinking.

Sue's behavioural problems started when she was a toddler and were characterised by repetitive behaviour and speech, heightened post-ictal irritability and aggressive acting out when her routine was disrupted or needs were not immediately met. Sue went to boarding school when she was nine. Patricia told me she started to abuse alcohol at the time to deal with her stress and anxiety about her daughter's epilepsy and intellectual disability. She also said that alcohol abuse became progressively worse and by the time Sue, now in her early twenties, went to a community-based residential care facility for people who have ID, Patricia was consuming more than 30 units of alcohol each day.

Sue's aggressive behaviour became exponentially more pronounced after she had developed post-ictal psychosis in the early years of young adulthood. Post-ictal behaviour typically lasted only a short number of hours following nocturnal seizures; her epilepsy reportedly remained intractable to the use of anti-epileptic drugs. Sue's problem behaviour eventually led to her expulsion from her residential facility, and at the time of therapy she had been living with her parents for ten years.

Patricia sought treatment for alcohol abuse and alcohol dependence. At the time of therapy, she had been abstinent from alcohol for longer than ten years. Likewise, her husband had successfully recovered from his addiction. Patricia continued to attend Alcoholic Anonymous meetings.

Patricia told me that she was constantly tired because her lung capacity was compromised due to emphysema. She also mentioned that she was receiving treatment for arthritis. Her husband was employed as an electrician. Patricia resigned from her secretarial work to oversee Sue's caregiving.

During the initial session Patricia reported high levels of parenting stress that she related directly to her daughter's aggression and Sue's persistent apprehension about forthcoming social and family events.

3.1.2 Case formulation

3.1.2.1 Predisposing factors

Many aspects of Patricia's psychological distress were underpinned by core beliefs that were shaped in early childhood. Her family history also confirmed a probable genetic predisposition for anxiety.

Her father was described as authoritarian with an explosive temper. Patricia told me that he often "abused with the mouth", especially when he was intoxicated. Patricia said that she learnt from an early age that her father was less likely to displace his anger and frustration on her if she kept a low profile. Looking at her mother for protection, Patricia's earliest memories of her mother was that of a helpless person who was dependent on benzodiazepines. Her mother reportedly experienced prolonged periods of intoxication, disorganisation and maternal absence. Moreover,

at such times she often retired to her bedroom to sleep off the sedative effects of prescriptive drugs.

Along with her father's unpredictable outbursts and emotional abuse, her mother's unavailability and negligent parenting prevented Patricia from developing trust in authority figures. When reflecting on attachment issues to assist with the case-conceptualisation, I noted many elements of fearful-avoidant attachment and pervasive relational ambiguity. As will be described later, her ambivalence extended particularly towards her husband.

I also observed that Patricia's family history suggested a biological predisposition for addiction and habit-formation in the use of substances. Besides her mother's reported anxiety, her sister had also received treatment for depression.

3.1.2.2 Precipitating factors

Against the background of her child's behaviour and other stressful life events that were maintained for many years, the precipitating factors were mostly responsible for an intensification of existing psychological distress. Most recently, Sue's repetitive behaviour had a direct negative impact on Patricia's stress levels: in the months leading up to the time therapy commenced, Sue started playing a CD of a well-known Irish boy-band when she was at home. Although her fixation sounds innocuous enough, Patricia told me that the constant buzzing and echoes continued throughout the night. Requests from Patricia or her husband to turn the volume down were frequently met with threatening behaviour and verbal aggression.

At the time of therapy, Sue's psychosis had persisted unremittingly for many years. Sue experienced visual hallucinations and paranoid delusions which made her suspicious and irritable towards her family.

3.1.2.3 Maintaining factors

Patricia's presented with symptoms of depression and high levels of parental stress that were maintained by the following factors:

First, the persistence of Sue's re-assurance seeking behaviour and verbal aggression provided Patricia with little opportunities for respite. Patricia told me that she continuously worried about the future recurrence of stressful caregiving events and behavioural outbursts. She also presented with prominent cognitive variables that consisted of rumination about adverse caregiving incidents in the recent past.

Second, Patricia's coping strategies very often aimed at "keeping the peace", which almost invariably denoted acquiescent responses to some of the unreasonable demands that Sue had made. For example, Patricia mentioned that she repeated lists of people and objects to Sue for hours at a time. Sue's inclination to list items pointed to possible traits of autism, and I believe that Patricia reinforced her daughter's re-assurance seeking behaviour in an attempt to mitigate the risk of acting-out should such repetitions be discontinued.

She also described herself as a "people's pleaser" and did her best to avoid conflict even when she was discontent about issues. Patricia described numerous incidents when her husband had overridden her efforts to become more assertive towards Sue. Patricia told me that her husband shared similar fears about potential catastrophic outcomes when Sue was "not given her way". By maintaining this negative cycle of reinforcement, Patricia had to exert considerable self-control. She also stated that she actively tried to escape and avoid situations where she either had to repeat information or deal with the consequences of not meeting Sue's demands.

Last, Patricia also suffered from emphysema, a chronic respiratory illness which has known associations with depression and anxiety disorders, fatigue, low energy levels and limited mobility (Goodwin et al., 2012). Towards particularly the latter part of psychotherapy, when the winter rains settled in, Patricia often complained about her chest, which prevented her from completing many of her daily household tasks.

3.1.3 Narratives of psychotherapy sessions

Session one

Patricia disclosed some of her background information during the interview that was scheduled before the onset of therapy. For that reason, I thought it inappropriate to pursue the same topics during the first session. More emphasis was therefore placed on ways of socialising Patricia to CBT. We also used the first session to formulate goals for therapy.

As was the case during pre-assessment and the interview, Patricia came across as feeling *heavy* and depressed. Further prompting confirmed the presence of major depression with the following symptoms: a depressed mood, low levels of energy, difficulty in falling asleep, inadequate concentration, feelings of helplessness and guilt. Whereas she used to enjoy going out with friends for coffee, she stopped doing this altogether. She also used to enjoy reading, but was no longer reading fiction of any kind. Patricia summarised her feelings as follows:

Patricia: I'll curl up; I want to curl up under my duvet and just die. That's how I feel!

She rated her levels of anxiety and depression between ninety and a hundred on subjective symptom checks. While only provisional, Patricia met some of the criteria

of generalised anxiety disorder: she described herself as “*a very anxious person; nervous all the time*”. Further discussion elicited apprehensive expectations about everyday events across a variety of activities. She found it difficult to control her worry.

Patricia attributed most of her feelings of sadness and hopelessness to her daughter’s behaviour. I was also struck by the intensity of Patricia’s feelings of fear towards Sue:

Patricia: By being fearful. Because I’m fearful of Sue. I’m scared, I am terrified!

Patricia’s parenting stress and constant apprehension were not only linked to the manifestation of eventual episodes of acting out. It was also based on catastrophic thinking about the possibility that demanding behaviour and verbal aggression might escalate into physical aggression.

Sue’s repetitive questioning, re-assurance seeking and listing were described as precipitating factors to Patricia’s symptoms of depression and maternal stress. Her daughter’s demands to repeat grocery lists and the names of family members who were attending forthcoming family events had by then become almost ritualistic. For example, if the family had a *braai* (barbecue), an activity Sue enjoyed, she usually insisted that her parents repeat a list of invited family members. Failure to repeat such lists often resulted in demanding behaviour and verbal or physical aggression. Patricia attributed much of her distress as the result of the energy it took to allay Sue’s anxiety.

We agreed on the following therapeutic goals: First, to try to reduce parental stress; second, to reduce depression and especially her feelings of helplessness; and third, to bolster her ability to cope with Sue’s specific problem behaviours.

Session two

Having had the opportunity to take some respite when she took part in a weeklong Alcoholic Anonymous outreach initiative in another city, Patricia told me that she was feeling marginally less depressed. However, symptom checks failed to confirm that her depression (100) and parental stress (90) had improved. She also continued to describe ongoing worry about everyday events.

Patricia recalled a caregiving incident over the weekend that led to heightened parental stress and feelings of sadness and a sense of helplessness. Whilst visiting relatives, on arrival Sue found out that her aunt's DVD player was not working. Her subsequent agitation and ongoing demands to "*fix the DVD*" increased Patricia's stress.

Patricia provided me with a sample of Sue's speech, which highlighted ASD problems with social communication and repetitive speech:

Patricia: Fix it, make it work, make it work! Please put it on, say that it's not broken; say it's not broken! It's not broken.

We used guided discovery and imagery of the event to explore Patricia's thoughts and feelings about the incident. Fortunately, the DVD player was repaired and Sue was able to watch her DVD.

Notwithstanding the fact that this volatile situation was successfully defused, Patricia described feelings of panic which were cognitively mediated by beliefs that her child will "cause a scene" and become verbally and physically aggressive. I also thought that Patricia felt embarrassed and angry by the incident. I reflected on a previous episode in the hospital's Out-Patient Department when Sue's demanding behaviour

in front of other clients had caused a visibly distressed Patricia to blush and apologise for her child's behaviour.

Patricia also worried that her sister, who she described as short-tempered, was going to lose patience with Sue. She told me that she was unable to enjoy the remaining part of their family visit and just wanted to go home.

The episode elicited helplessness and intense feelings of anger:

Patricia: Like I can . . .

OC: Ja?

Patricia: . . . easy, take her, hit her against the wall and say: "*Enough!*"

OC: [inaudible segment]

Patricia: But I will never do it, I can never do it, but I mean, I would never . . .

OC: [cross talk] Mm-mm!

Patricia: But the thought comes to mind.

OC: But I think the fantasy also shows us how helpless you felt at the time, and . . .

Patricia: [interjection] Absolutely, absolutely helpless! Like I didn't want to be there, and I don't want a scene here, in somebody else's home! And once again, and . . .

OC: Ja?

Patricia: . . . and once again, I felt helpless, I was stressed to the max!

Session three

Patricia's symptom checks improved from initial ratings of 100 for depression and 90 for parental stress to 70 on both accounts. She attributed the modest gains to the fact that Sue had not displayed severe behavioural difficulties during the previous week.

Patricia mentioned that she continued to feel stressed even though Sue's behaviour had improved. We used guided discovery to identify her underlying beliefs about the impact of Sue's behaviour on her own psychological well-being. It emerged that Patricia constantly anticipated possible behavioural outbursts, even in the absence of cues to signify the onset of outbursts. Such beliefs maintained elevated levels of parental stress and constant vigilance:

Patricia: When she came through the lounge which was slightly *deurmekaar* . . . (in disarray). She turned around; she went back to her room and . . . (sighs). There was no drama, so if I could just learn how to . . . not . . . you know? Stress – looking for something that hasn't happened yet!

For the first time in many years, Patricia decided to leave Sue at home when they attended a family barbeque at her sister's house. Although Patricia said that she felt relieved after she had made this decision, she also described apprehension and worrying thoughts about the possibility of Sue having behavioural outbursts while she and her husband were visiting family. She was also worried that her youngest daughter did not have the patience and skills to manage Sue's behaviour. I noted cognitive dissonance: while Patricia wanted to spend more time pursuing her own interests and have a social life separate from her daughter, she also told me that she

had to take responsibility for Sue's care by having her child attend social events with her. In addition, she described feelings of guilt for having left Sue at home.

Sue's presence at social events also reduced Patricia's uncertainty as to whether behavioural outbursts would occur if she was left at home. We discussed the uncertainty and worry that Patricia had experienced during that time. It is possible that Patricia's previous insistence in having her child accompany them to family events could have constituted a degree of uncertainty avoidance.

In this session, psychoeducation about the usefulness of mini-respite opportunities to pursue her interests proved largely ineffective. Patricia continued to describe dichotomous beliefs about her caregiving responsibilities: either Sue attends these events with her, resulting in her own unhappiness, or she "*selfishly*" leaves Sue at home to pursue her own interests.

Patricia also told me that she felt isolated and alone with her husband in their constant efforts to accommodate Sue's needs because she received minimal support from her family and her other two children.

Session four

Symptoms checks of parental stress and depression remained unchanged on 70.

The homework assignment required Patricia to consider the levels of family support she had received from her husband, children, sisters and other members of her family in managing Sue's behavioural difficulties.

Patricia told me that she started to increasingly think about her family's lack of support. She believed that Sue's exemplary behaviour during the course of the previous week was only because of their willingness to meet all her daughter's

requests and demands. Patricia also identified specific events that had caused her parental stress, a sense of helplessness, and anger:

Sue continued to play one CD throughout the night. She also continued to demand that Patricia or her husband reset the CD-player at different intervals during the day or at night. Patricia told me that she wanted to become more assertive towards Sue and challenge her daughter's demands, which she saw as a form of manipulation and acting out.

However, in what constituted a double bind, her husband, Peter, would try to "keep the peace" and "come running" whenever Sue's demands became persistent. In the process he had often overridden Patricia's ideas that they should challenge Sue's fixations in a more confrontational manner:

Patricia: If I ask them to do something. If I ask them . . . they will do it. Not whole-heartedly . . . (long pause). Uhm, Peter just does everything for Sue to keep the peace; he'll bend over backwards! Just to save a scene; to save some drama. Sometimes I feel . . .

OC: Hm?

Patricia: Not always, but I do have this feelings at times: if she's gonna break something, let her break it! Because we can't keep on . . . we're suffering to keep her happy!

OC: Ja?

Patricia: And sometimes I do feel: if she's gonna break the window, let her break it, let her hit it broken! Because we can't keep on trying to keep the peace;

everyone else is suffering for it. We can't have a conversation in the house. We can't do things; we can't go somewhere.

Sue's insistence that the music continue to play throughout the night prevented Patricia from having a good night's sleep. Pervasive psychosis and its associated paranoid delusions led Sue to believe that actors on the television actively disliked her. She therefore made increasingly bizarre demands that her parents should reprimand the TV characters for gossiping about her. Patricia was understandably highly uncomfortable with her daughter's directives.

At other times Sue tended to become visibly distressed after she had observed alterations in the facial expressions or demeanour of her parents. Such shifts of affect, body posture or facial expressions could be subtle or pronounced; and changes in non-verbal parental behaviour did not necessarily relate to caregiving events. Patricia provided an example of her daughter's behaviour: when she was busy in the kitchen, Sue entered the room and observed a slight frown. Within moments, she became highly agitated and started screaming: "Why is your face like that? Why do you look like that?"

In such situations, Sue would often ask her father to tell Patricia to change her facial expression. In most of these instances Peter met Sue's requests even if it meant that such actions directly opposed what Patricia was doing. He tried to keep the peace, but Patricia was feeling increasingly ridiculed and angry towards Sue and Peter about the way she was treated by both of them.

Patricia: *"Just tell Mommy she's not the boss, you're the boss!"*

OC: Hm.

Patricia: In other words . . . No, she likes . . . I can't explain it. She's . . .
When she's, then Peter will say: "*Yes, yes, Sue, you're quite right, you're quite right!*" And then I get these angry thoughts: why is she playing the one up against the other?

From discussion, I observed that Patricia held conflicting views about avoiding possible behavioural outbursts by giving in to Sue's demands. Because of catastrophic thinking, persistent worrying and apprehensive expectations about her daughter's behavioural outbursts, part of her agreed with her husband, even if it made her feel hurt, angry and disempowered. Yet she also believed that they should be more assertive towards their daughter.

Guided discovery was used to identify catastrophic automatic thoughts and her beliefs that Sue was intentionally acting out. We also explored her beliefs that Peter was giving in to demands because he too was fearful of his child's aggression. Because Patricia was finding it difficult to separate feelings from beliefs, e.g., descriptions of anger as beliefs, the homework assignment for the next session was to complete a Dysfunctional Thought Record about caregiving events. I also continued to use the events Patricia had mentioned to socialise her into the CBT model.

Session five

Patricia's subject symptom checks continued to measure at ratings of 80 for depression and parental stress.

She was tearful and sad throughout the session, again linking her prevailing mood and apprehension solely to Sue's behavioural difficulties. Patricia described an

incident when Sue lashed out at her after she had suggested that her daughter should scrape less margarine over her bread.

From information in Sue's hospital folder and Patricia's feedback, neurologists and psychiatrists had in the past two or three years made direct links between the frequency of Sue's nocturnal seizures and her behavioural difficulties. Patricia confirmed that Sue's seizures had increased in frequency and severity during the course of the last week.

While Patricia had extensive knowledge about epilepsy, she had received minimal professional input about the role of psychosis and autism in Sue's behavioural difficulties. I subsequently provided psychoeducation that covered symptoms of psychosis. We linked some of her daughter's aggression and irritability to post-ictal psychosis. I also covered some of the basic autism-related behaviours in Sue's profile, e.g., repetitive speech, obsessions and her daughter's challenges in terms of social communication and social interaction.

Socratic dialogue uncovered catastrophic beliefs and images that were activated prior to, during and after episodes of behavioural outbursts, namely that Peter may get seriously injured or go into cardiac arrest when Sue displayed physical aggression towards them.

OC: What is. . . I do want us to just focus a bit on what's going through your mind when Sue is lashing out at you. What are you thinking about?

Patricia: Is she gonna hurt, is she gonna hurt because I'm getting really fearful lately. Is she gonna hurt Peter?

OC: Peter? To what point is she gonna hurt Peter? Do you have an image (of this in your mind)?

Patricia: Is he gonna have a heart attack? Because he stresses so much:

"Please Sue, stop it Sue!" And he's shouting: "*C'mon baby, calm down!*"

And she's going ballistic and he's begging her from deep down. Begging her:

"Stop now! Don't hurt yourself!"

Consistent with typical beliefs experienced by persons with generalised anxiety, Patricia's saw functionality behind her apprehension and worry (Simos & Hoffmann, 2013). Hence, I believe that on a metacognitive level she perceived her idea of being "on guard for twenty-four seven" as a way of exerting control over unpredictable caregiving events.

When we went through previous episodes of her daughter's aggression, Patricia realised that Sue's verbal and physical aggression were on average only present for three days of the week. Sue also attended a workshop during the week and Patricia was often able to identify cues and triggers that would activate her daughter's verbal or physical aggression.

We were therefore able to modify beliefs to represent a more balanced view: Sue's behavioural outbursts were not present all the time; there was respite between episodes.

Towards the end of the session we started talking about low arousal approaches to manage her daughter's behaviour. The use of positive behaviour support was also tentatively introduced as a possible way of managing Sue's behaviour.

While Patricia and Peter were already employing positive reinforcement, Patricia had some doubts as to whether it yielded any results. I was impressed with her insight into the need to have a low arousal environment; at the time they had already created such an environment at home – this was done without professional help and based on astute observations that low expressed emotion and adherence to a structured routine and predictability lowered the frequency of aggressive behaviour. The problems of their management approach was more in the lack of follow-up conversations once Sue was out of crisis; and the corresponding absence of consequences to change Sue's behaviour in future (McDonnell, 2010). By letting Sue have her way when she demanded that her needs were immediately met, Patricia also felt that they were preventing Sue from developing the patience to wait for the requested items or actions.

Session six

Patricia's symptom checks for depression and parental stress remained high at 70 and 60 respectively. She stated that she was "stressed to the max". Self-rating scores remained elevated even though Sue's behaviour had improved markedly from the previous week.

For the second time, Patricia left her Dysfunctional Thought Record at home and we allocated time at the end of the session to make sure she understood the rationale behind the exercise.

The identification and modification of negative automatic beliefs that related to the management of Sue's aggression, demanding behaviour and repetitive speech were placed on the agenda. Patricia was able to identify a recent caregiving event which caused her considerable distress:

- Situation or event: Peter gives in to Sue's repeated demands to visit a restaurant without consulting Patricia.
- Automatic thoughts: "She's not gonna learn that she can't treat us like this"; "He pacifies her all the time"; and "I want to reprimand her."
- Emotions: Anger, disappointment and sadness.
- Behaviour: The family goes to the restaurant. Patricia keeps quiet despite her anger towards Peter.

In fact, Patricia stated that she got so angry with Peter that she *"wanted to hit him."*

Guided discovery was used to identify similar events in which Peter continued to *"keep the peace"* notwithstanding Patricia's reservations. Similar to reports in sessions four and five, Patricia continued to experience conflicting beliefs that they had to give in to Sue's requests in order to prevent behavioural outbursts:

OC: Last week we also covered a bit, you know, even though – and Peter is supporting you so much –

Patricia: Ja.

OC: . . . the type of support is not always optimally supportive. Have you given that a bit of thought?

Patricia: I have given that a lot of thought! The way he's supporting the situation with Sue. . . If he didn't do that, I've been thinking about it, maybe we didn't be so protective. It will be 10 times worse!

We continued to explore and unpack Patricia's opposing views with reference to her husband's way of managing Sue's demands and aggression. Patricia also disclosed that she felt worried and stressed about various other life events. For example,

when driving with her husband, Patricia continuously worried about the possibility they might be involved in a motor vehicle accident:

Patricia: (Long silence). I can't say . . . You know, I'm stressed, a really stressed out person. So I can't say it's gonna be any better, I don't know! But I don't, for the week that stressed about what happened this week.

OC: Mm. Mm.

Patricia: But I'm always a very stressed person, even when driving.

OC: Ja.

Patricia: I'm panicking already for the cars that's not even gonna come past us. So I am a stressed out person!

As described in the following excerpt, there were indications that Patricia was re-negotiating her management style regarding Sue's behaviour. There were different indications that Patricia was becoming more assertive towards Sue. Patricia decided not to give in to her daughter's demands one evening during the previous week:

OC: Okay, so this time around you didn't . . . you didn't get up. And. . . ?

Patricia: No, I didn't. She came to me. An hour later, she came to me and said: *"Yes, and what's happening?"*

OC: Yes. And what was going through your mind when you decided you're not going to get up?

Patricia: I smiled inside myself and I thought: *Ah-ah, what's going to happen now? Please . . . And I actually said a prayer: Please God, let this be, let this end up to be a peaceful night!*

The decision to deviate from normal routine caused Patricia considerable anxiety and uncertainty. However, as opposed to Patricia's previous anticipation of behavioural outbursts when she refused to meet Sue's requests and demands, the expected outcome of Sue becoming aggressive and irritable did not materialise.

Session seven

Patricia's mood had deteriorated markedly since the last session and her parental stress remained elevated: she described feeling exhausted and overwhelmed by the demands of caregiving. Sue did not display aggression during this period but refused to go to work one morning. Sue also continued with repetitive speech and demands that her parents repeat information. On one occasion, Patricia refused to repeat a list of family members who were attending dinner on Good Friday. She told me that she became angry and she subsequently decided to leave the room when Peter had started to repeat the list on her behalf.

Having again voiced conflicting feelings about her husband's intervention, the Downward Arrow technique was used to delve deeper in order to establish the meaning of her husband's behaviour towards her. The following excerpt formed part of a longer discussion during which I gently challenged Patricia to think critically about her perceptions of why Peter continued to override her caregiving decisions:

OC: (Inaudible segment) What does it mean about the way in which Peter actually treated Sue, and by proxy, you? What's the meaning of it?

Patricia: [interjection] It's like encouraging her to carry on.

OC: And?

Patricia: That's what I felt; that's why I was angry . . . He was encouraging her to . . . You know? Not that he did it out of spite.

Observing a mood shift during discussion, when I prompted her Patricia told me that she wanted to become more assertive towards Sue on that day because she thought it was unlikely that her child would display aggression:

Patricia: I do realise that there would've been a big possibility that she wouldn't have acted out. That's why I said: *"Finish! No more! I told you!"*
So, I do know there are times. And I'm willing to take that chance!

It eventually transpired that Patricia was generally in agreement with Peter that they should give in to Sue's demands during periods of increased aggression and acting out. At other times they must be more assertive towards their daughter:

Patricia: But, it's not all that helpful because . . . we could try and work this together. (Silence) And I might decide, ja, I rather keep the peace. But I feel there is, are times that she can . . . When *"No"* is *"No"*.

By repeating the list even though Patricia thought they should have challenged Sue's obsessions, Patricia became resentful towards Peter and the manner in which he treated her in front of Sue:

Patricia: He's not keeping the peace! Because . . . I'm . . . might've been quiet about it on Saturday and not angry towards him afterwards, but I am . . .
(Long silence, sighs) You know, me and words or feelings: I'm resentful towards him!

Another mood shift was noted when Patricia realised that her resentment was the result of her husband's dismissive attitude and not only because of Sue's behaviour.

This realisation afforded her the opportunity to increase her agency and she subsequently decided to engage with Peter about their management of Sue's behaviour. She told me that she intended to voice her discontent regarding some of his current behaviours towards Sue.

Session eight

Patricia's symptom checks ranked lower for parental stress and depression at 60 and 50 respectively. She attributed her improved ratings to a combination of factors:

First, she experienced Sue's repetitive speech, demands and re-assurance seeking behaviour as less intrusive than before:

Patricia: You know, and she always asks me to say . . . No! The repetitiveness is still there.

OC: Mm. It's not having as much of an impact on you though?

Patricia: Yes. Definitely not.

Second, Sue had not displayed severe behavioural outbursts during the course of the last week. Third, Sue stopped playing the same music throughout the day and night. Last, Patricia had an open discussion with Peter during which she reiterated the need to gently challenge Sue's obsessional behaviour by working together.

We covered behavioural activation weeks earlier, but it was only during the last week that Patricia went out to buy a book to read. She also went for a pedicure, something she had not done in years.

We discussed the use of low-arousal approaches to manage Sue's behaviour, because there was a high probability that her daughter's behaviour would deteriorate

again. After I had previously provided her with the website of Autism South Africa, Patricia read up extensively on the subject of autism. She told me that her child's behaviour was now making much more sense.

As a homework assignment, I asked Patricia to laminate photos of her family members. The rationale was that pictures could be used as an augmentative visual aid if Sue requests the repetition of names of family members. Patricia did not appear very motivated to do this assignment.

Whereas it was a productive session with promising indications of therapeutic change, I was worried that a relapse of Sue's behaviour would again result in higher levels of parenting stress.

Session nine

Patricia was visibly anxious and tearful at the start of the session. She stated that Sue had a number of episodes of verbal and/or physical aggression. For example, when Patricia refused to allow Sue to cut out photos of her grandchild from an album, Sue threw a cup at her and threatened to harm her:

Patricia: I was scared, I was crying. Try not to let her see I was . . . you know, I was scared and crying (tremor in voice discernible). But it was a horrible, horrible experience which didn't happen for a long time.

Autism-related obsessionalities continued unabatedly, and a visit to the psychiatrist confirmed that Sue was acutely psychotic with paranoid delusions and visual hallucinations. Because of her child's increased behavioural outbursts and repetitive speech, Patricia ranked her anxiety and depression at 90 and 70 respectively:

Patricia: It wasn't every day that was bad . . . it was the constant, uhm . . .
(long period of silence) repeating that was hectic. But we try to work to-
together, but . . . We spoke about it, Peter and I and the kids. Uhm, (sighs)
just to try and . . . If she (asks?) to a standstill and listen, just to do it!

The excerpt captures some of the codes which repeatedly emerged from the thematic analysis of the session: Patricia employed various ways of coping to manage her daughter's behaviour, albeit with limited success. She accepted responsibility by trying to manage her child's behaviour, and sought social support from her husband and children. She also tried to problem-solve ways of enhancing consistency and predictability in their management of Sue's behaviour by getting everyone to employ the same strategies.

It was at this point that I read through earlier transcripts and codes which were collated against psychometric assessment that was conducted after Session 4 and Session 8. It was evident that Patricia progressively used a wider selection of coping strategies to deal with Sue's behavioural problems; and pre- and post-assessment scores on the Ways of Coping Questionnaire doubled from baseline scores.

Two discussion points were put on the agenda. First, we discussed different group home and community-based residential care options for Sue to address Patricia's previous concerns about her daughter's future care, should anything happen to her. Second, we continued discussion about the use of low arousal approaches to manage her daughter's behavioural difficulties. The focus was on management strategies to cope with her daughter's behaviour if such behaviour escalated into crisis.

Discussion also revolved around cues that activated behavioural outbursts.

Patricia's previous descriptions of helplessness and an external locus of control were in part valid because Sue often responded with heightened arousal and agitation to internal cues: Patricia had limited control over her child's epilepsy, psychosis and autism. Moreover, autism and post-ictal psychosis were often linked with behavioural disorder, albeit that such internal factors were in complex interplay with interpersonal and other ecological variables, e.g., when her parents refused to give in to unreasonable or unrealistic demands.

Psychoeducation again attempted to qualify the impact of Sue's mental ill health and developmental disorder on her behaviour, thereby furthering Patricia's understanding of complex antecedents and setting events that activated and maintained Sue's problem behaviours.

The adverse events that occurred during the week also reignited memories of past caregiving adversity and trauma. Patricia recalled the time when Sue was placed in a community-based residence more than a decade ago. At the time Sue was heavily sedated and "drugged", which according to Patricia was the only way the poorly-staffed community-based residence was able to manage her behaviour.

Patricia stated that this led to feelings of guilt; she also told me that she compensated by "*spoiling*" Sue when she visited their home during weekends. Patricia also made links between earlier "*spoiling*" and their current difficulties to manage Sue's demanding behaviour and subsequent acting out.

Session ten

Patricia ranked her mood and anxiety at 60 and again attributed the slight improvements to Sue's lack of aggressive behaviour during the course of the previous week, although her daughter's autism-related behaviours persisted.

The following discussion points were placed on the agenda:

- The option of making a referral to her medical practitioner to consider pharmacological treatment for depression and anxiety.
- Exploring the role of early life experiences and formative parental influences on her present beliefs and behaviours about parenting and Sue's behaviour.

Patricia recounted distressing and traumatic earlier parental experiences when she had to stand by helplessly while Sue, as an infant, had numerous generalised tonic-clonic and absence seizures. She described the need to be constantly vigilant to prevent her child from having physical injuries. Patricia also recalled her constant fear that her child would die whilst having a seizure.

She recalled another incident that occurred approximately eight years earlier when Sue had developed pneumonia which led to hospitalisation. Patricia's repeatedly requested nurses to monitor Sue to make sure she did not remove her oxygen mask. Nonetheless, she received a phone call the next morning informing her that Sue was being resuscitated after the mask had come off during the night.

Having worked with Patricia for ten sessions, I identified the following core beliefs from our previous work:

- I am vulnerable.
- The worst will happen (with my child).

- I am unable to protect my child.
- The world is a dangerous place.
- I am not safe.
- I am helpless.
- I am scared.

Patricia became tearful and distressed when she recalled earlier childhood events that revolved around the explosive temper of an authoritarian father, an absent mother and the substance abuse by both parents. I conceptualised her earlier childhood experiences as reinforcing a sense of vulnerability, helplessness and a need to be constantly alert about possible temper outbursts from her father.

Sue's contemporary behavioural outbursts activated similar catastrophic beliefs and perceptions of maternal vulnerability and helplessness. Such beliefs were centred on the dangerousness and potential threat of Sue's behaviour towards both parents:

Patricia: Like if I had the whole morning, then fine! But I still had to do some stuff for Peter and I thought I don't have time to stand here and explain all this.

OC: Mm.

Patricia: And I walked away, thinking, you know, whatever.

OC: Bear with me now: when that was happening, what was going through your mind this time?

Patricia: *J**** Ch****, not again!*

OC: Okay. Now, go back to the seizures and when she was a baby and having those seizures. What was going through your mind at the time?

Patricia: [pause] The same thing!

OC: Okay, so why . . . ?

Patricia: [cross talk] Not as bad, not as . . . it was worse then.

OC: Of course it was worse!

Patricia: It was worse then!

OC: *But J****, not again!* When she was having a seizure, what was [sic] your fear(s)?

Patricia: I was fearful, scared that she's gonna hurt herself.

OC: Or die?

Patricia: Yes! Yes! I always thought the worst.

OC: Okay.

Patricia: I always thought the worst is gonna happen to her.

OC: (speaking softly) As if it isn't terrible enough to . . .

Patricia: Hm. We always used to ask the doctor, can, you know, what can happen to her? And all he used to say to us were: "*See that she can't hurt herself.*" (Sighs) Ja!

OC: Can you . . . Do you have any idea of how strong the belief system developed because of the intensity of your emotions as a young mom? *J****, not again! She's gonna die! Or hurt herself badly.*

Patricia: Mm! Mm.

OC: That's . . . Those are the thoughts, okay? And it led to very intense emotions
. . .

Patricia: Mm.

OC: Maybe you kept some of those thoughts, because today when she looks as if she might become aggressive, what's going through your mind?

Patricia: Hmm . . . The same thing, *J****, here we go again.*

OC: [cross talk] Here we go again, because she's going to . . . ?

Patricia: Either that she's going to go ballistic, she's going to hurt one of us; I get scared, I get scared . . .

We explored the consequences of Sue's more severe behavioural outbursts:

Patricia realised that Sue's physical aggression tended to de-escalate rapidly after her initial outbursts. While verbal outbursts often continued after displays of physical aggression or destructive behaviour, Sue would typically revert to repetitive verbalisations such as: "*It wasn't me! Say it wasn't me! Say it wasn't me!*" Patricia also never had to seek medical treatment after episodes of physical aggression were directed against her. Without minimising the validity of fearful and distressing maternal responses to behavioural acting-out, evidence suggested that the worst-case scenarios in the past did not result in significant physical injury to Sue, Patricia or Peter. From our discussion it became apparent that Patricia used verbal aggression as a cue to predict physical aggression, whereas verbal aggression is in fact a poor predictor of physical aggression (e.g., Cooper et al., 2009; McDonnell, 2010).

Session eleven

Patricia's anxiety levels were again rated at 60 but she ranked depression at 90.

When I asked her why her mood had deteriorated, Patricia responded that she was worried and saddened by her son's possible relapse into the use of marijuana:

Patricia: So of course I am sad. I must say that with my stress levels . . . isn't so high with Sue, but you've got to look at each and every individual. No! Like I say I could've been worse.

Patricia also indicated that she was starting to think differently about the severity and duration of Sue's behavioural outbursts:

Patricia: If she's gonna perform now, just think "*Agh!*" What I'm trying to do, if it does happen, unfortunately (chuckles). It didn't happen this week, but I'm glad nothing happened! If something happens, and she's gonna throw her toys out her cot, I must just try and remember it's not that bad! This is gonna be going a couple of minutes.

Patricia also stated that she was unhappy about the amount of time her other two children spent at home. They expected her to cook for them and their partners; apparently they also slept over for the sole purpose of watching cable television. She was also unhappy about the number of times she had to babysit her grandson. Her husband continued to provide financial support to his other children despite Patricia's reservations and repeated requests to have more space and privacy at home:

Patricia: Maybe I'm being spiteful but at this stage of my life I've had children at a young age. I'm still sitting with them and I haven't had a break from them.

Patricia attributed *all* of her parental stress to Sue's behaviour in earlier sessions. In this session, Patricia openly attributed her parental stress to her son's possible use of marijuana.

Sessions twelve and thirteen

Patricia's symptom checks for anxiety and depression stabilised at 60 during Sessions 12 and 13. Sue had not experienced significant verbal or physical aggression, although repetitive speech and autism-related obsessionalities continued.

In Session 12, Patricia stated that she was no longer worried that her son abused marijuana after she had received reassurance from his fiancé that this was not the case.

Patricia bought Sue gifts as a token of thanks for her good behaviour. Being in the last stages of psychotherapy, the use of positive reinforcement and praise for desirable behaviours was put on the agenda. The use of stimulus control to maintain a low arousal environment was also covered; and one of Patricia's greatest concerns was that her other two children and their partners often did not respect her and Peter's repeated requests to keep the noise levels down. Sue tended to become irritable in noisy environments. Similar to the previous session, she also described a sense of unhappiness about the amount of time her children spent at their home.

Patricia's apprehensive expectations and constant worrying about everyday life events were covered in more detail during the last two sessions. She repeatedly stated how she would worry that something would go wrong when she was busy with

routine and everyday tasks. She again described her fear of motor vehicle accidents.

In the last session, Patricia also provided two examples of anxiety-provoking events. She considered her anxiety as disproportional to the events that took place: The first example was when they assisted her daughter with moving into another apartment. Patricia stated that her emphysema caused her respiratory distress and she also felt "useless" and guilty because she could not assist with most of the more physical tasks that were associated with moving furniture, unpacking, etc.

Patricia also recalled how her grandson's birthday made her nervous to the point where she became nauseous, worrying about all the people at their house and whether anything would go wrong.

Patricia's perceptions about the danger and risk involved in Sue's outbursts of physical aggression continued to reflect a more balanced and less catastrophic view:

Patricia: I always got a feel of Sue coming up behind me; and she does attack from behind . . . with the fists. You know, but then again how-how much is she gonna hurt me? But I must remember how I never thought of it before that while we're scared. Well, we're scared, but lately I realised: How hard is she gonna hurt me? How much is she gonna hurt me?

3.1.4 Interview after psychotherapy had been terminated

Patricia's honest feedback about the psychotherapy process was insightful and helped me to plan subsequent case studies. When Patricia told me that she became very sad during various times of intervention, I realised that the battery of tests did not cover maternal depressive symptoms.

Patricia's feedback therefore informed my decision to introduce the Beck Depression Inventory II (BDI-II) as a measurement of mood before the start of each session in four of the succeeding five case studies.

Patricia described marginal improvement in parental stress and symptoms of depression. She told me that she continued to be constantly apprehensive about Sue's behaviour because she had little control over it. I thought that the strong relationships between Sue's epilepsy, psychosis and behavioural outbursts validated Patricia's perceptions about having limited control over her daughter's behaviour.

As described in the narratives, it would also appear that most of her negative affect and stress were caused by her ongoing worry about Sue's behavioural difficulties, and of course her experience of her daughter's behavioural outbursts and obsessional behaviours.

Patricia regarded the best outcome of psychotherapy to be the gains she had made in terms of coping: she told me that she learnt to cope better with Sue's behaviour. The Ways of Coping Questionnaire confirmed that she employed more coping strategies than at the onset of therapy.

Accordingly, psychotherapy failed to empower Patricia to significantly reduce her anxiety levels and dysphoria with regard to her caregiving challenges.

Notwithstanding our focus on the management of aggressive behaviour through the implementation of low arousal strategies and skills training, Patricia's locus of control and subjective assessment of controllability did not improve substantially.

3.1.5 Themes that emerged from thematic analysis

Theme	Excerpt
Maternal mental health concerns: Depression with prominent guilt, self-blame, hopelessness and indications of generalised anxiety	<p>Patricia: I'll curl up, I want to curl up under my duvet and just die. That is how I feel!</p> <p>—</p> <p>Patricia: I'll be sitting here crying my eyes out, but it's lifting me up, knowing I'm getting a break.</p> <p>—</p> <p>Patricia: So . . . (long pause). I've been feeling guilty for... so long... And, not doing what I should do.</p> <p>—</p> <p>Patricia: I think I've said it a lot of times: <i>"I wish I didn't live anymore"</i>. Uhm, I wish I could just sleep at night, wake up . . .</p> <p>OC: Mm.</p> <p>Patricia: . . . and then I feel guilty, immediately. I do feel guilty.</p> <p>—</p> <p>Patricia: (Long silence). I can't say... You know, I'm stressed, a really stressed out person. So I can't say it's gonna be any better, I don't know! But I don't, for the week that stressed about what happened this week.</p> <p>—</p> <p>Patricia: But I'm always a very stressed person, even when driving.</p> <p>—</p> <p>Patricia: I say: <i>"Ja, sure"</i>, not happily. And drawing closer to the time, I'm vomiting and...</p> <p>OC: You're really anxious.</p> <p>Patricia: Mm. That's what happens! And it doesn't have to be like that!</p>
Maternal physical health concerns as having a negative impact on Patricia's ability to complete everyday household and caregiving tasks	<p>Patricia: A long time and also . . . if I was a healthier person, if I didn't have emphysema, if my hands wasn't sore, I might feel a little bit better about doing things. But, everything I do . . . Even if . . . even if I didn't get emphysema and</p>

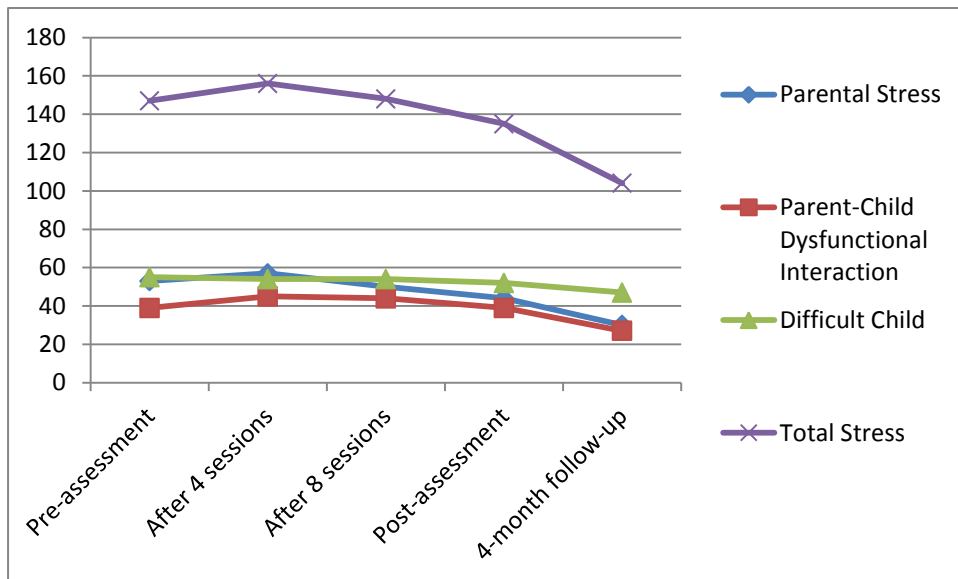
	<p>my hands didn't feel sore I would've been, for years I've been feeling down as far as Sue is concerned, but more so with the behaviour problem.</p>
<p>Parental stress because of Sue's behavioural difficulties</p>	<p>Patricia: I'm not . . . It's not only because of Sue but Sue messed up my . . . Not Sue messed up my nervous system. I never drank before I had Sue . . . And I became a nervous wreck!</p> <p>— Patricia: My-my mind is like . . . zonked. I can't think anymore. I mean, when she's around, I cannot cope!</p>
<p>Negative perceptions and other beliefs as maintaining conditions of parental stress: Catastrophic thoughts and an external locus of parental control</p>	<p>Patricia: Yes, more sad and disappointed for the way things are. And . . . not being in control.</p> <p>— Patricia: I can't deal with it the way I was, thinking the worst, I just got to be more positive and remember: she ain't gonna hurt me! I learnt that I don't have to be so fearful of her.</p>
<p>Caregiving through the decades: Distressing formative influences as having an impact on contemporary beliefs about caregiving</p>	<p>OC: Okay. Now, go back to the seizures and when she was a baby and having those seizures. What was going through your mind at the time?</p> <p>Patricia: [pause] The same thing!</p> <p>OC: Okay, so why . . . ?</p> <p>Patricia: [cross talk] Not as bad, not as . . . it was worse then.</p> <p>OC: Of course it was worse!</p> <p>Patricia: It was worse then!</p> <p>OC: But <i>J****</i>, <i>not again!</i> When she was having a seizure, what was [sic] your fear(s)?</p> <p>Patricia: I was fearful, scared that she's gonna hurt herself.</p> <p>OC: Or die?</p> <p>Patricia: Yes! Yes! I always thought the worst.</p>

	<p>OC: Okay.</p> <p>Patricia: I always thought the worst is gonna happen to her . . . Hm. We always used to ask the doctor, can, you know, what can happen to her? And all he used to say to us were: "See that she can't hurt herself". (Sighs) Ja!</p> <p>Patricia: Anxiety. I'm full anxious. When Sue is around, I'm anxious all the time!</p> <p>OC: Yeah, anxious.</p> <p>Patricia: It used to be only for the seizures . . .</p> <p>OC: Mm-hm.</p> <p>Patricia: I was anxious she's gonna have a fit . . .</p> <p>OC: Ja?</p> <p>Patricia: You know, are we going to hear, are we going to be ok but we've come to deal with it. We're talking about the here-and-now?</p> <p>OC: Yeah.</p> <p>Patricia: For now, it's just, having Sue's around I'm stressed.</p>
<p>A stiff upper lip and non-assertiveness to keep the peace: Feeling ambivalent, angry and conflicted about her husband's support in the management of Sue's behaviour.</p>	<p>Patricia: To keep the peace. Whereas I . . . if I had my way, I will say: "<i>What the h**l do you want? Can't you wait?</i>" You know? And I can't do that! Besides, if I did do it she'll freak. And besides, Peter is keeping me back all the time.</p> <p>Patricia: That's why I came out of the room, not being angry with him. I realise he wasn't being spiteful to me, but I thought this man is also driving me insane!</p>
<p>A lack of caregiving support from her other children and relatives</p>	<p>Patricia: You know? When the crunch comes, they're not really that supportive. They'll rather back away and disappear. And because they don't know how to deal with Sue's either, I suppose! You</p>

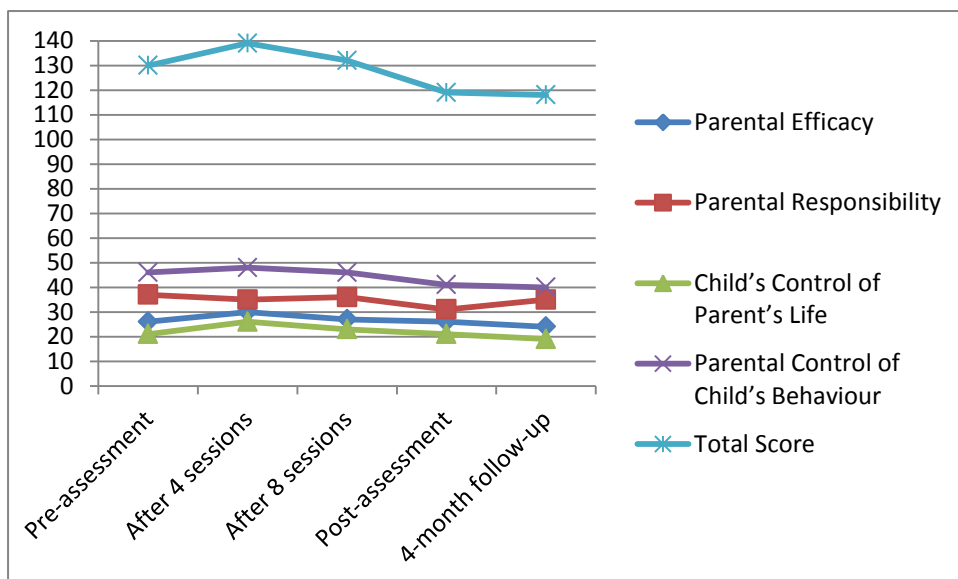
	know?
“I’m not sure it will work but I will try”: The use of an increased number of coping strategies to manage Sue’s behaviour	Patricia: A lot of it was good – good stuff, because I could cope better. How can I say? I can cope, I can cope better with Sue. It’s given me more insight to her problem(s), and I can help my children at home, which I’ve already done a little bit. You know? Letting them see the big picture. And for once they can learn something from me.

3.1.6 Psychometric test results

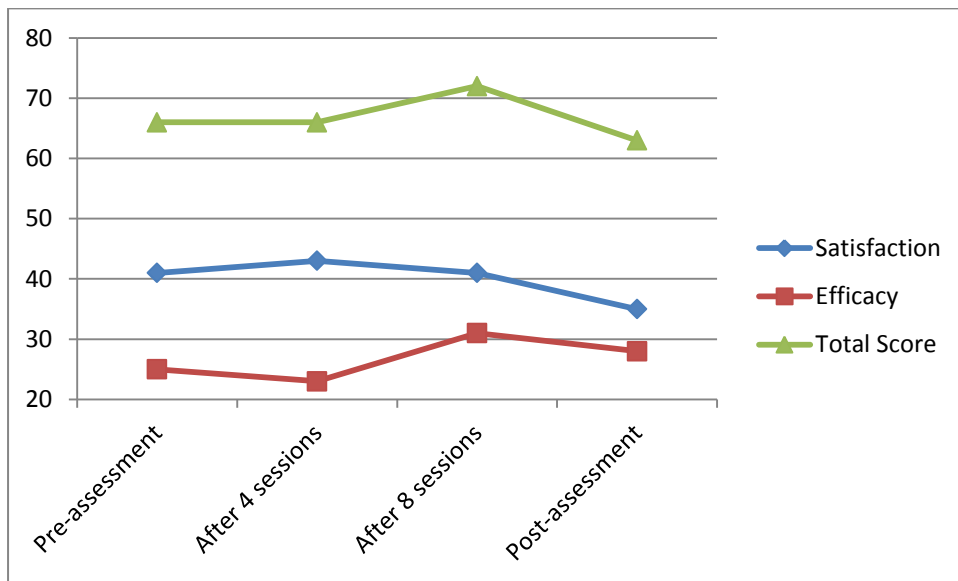
The Parenting Stress Index: Short-Form (PSI-SF)



The Parental Locus of Control Scale

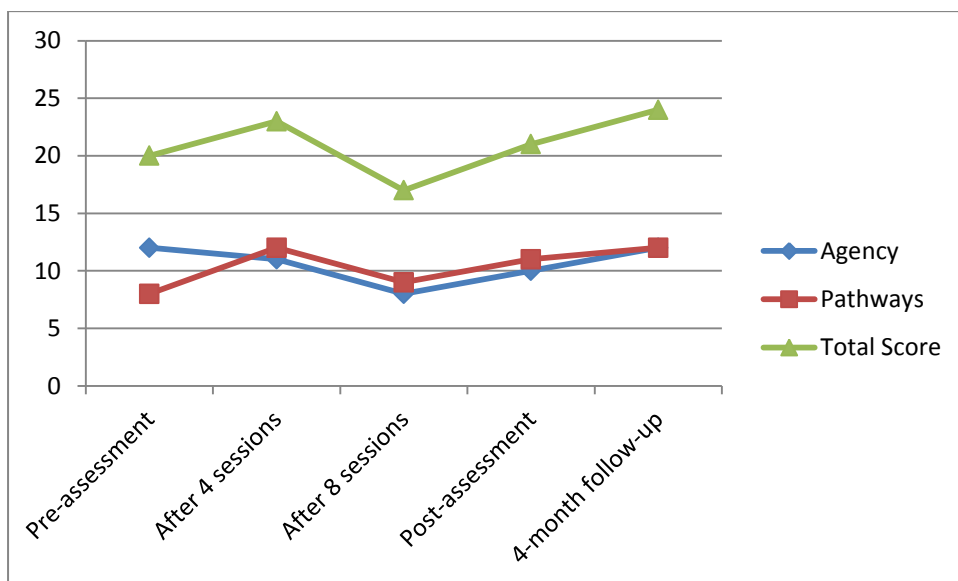


The Parenting Sense of Competence Scale

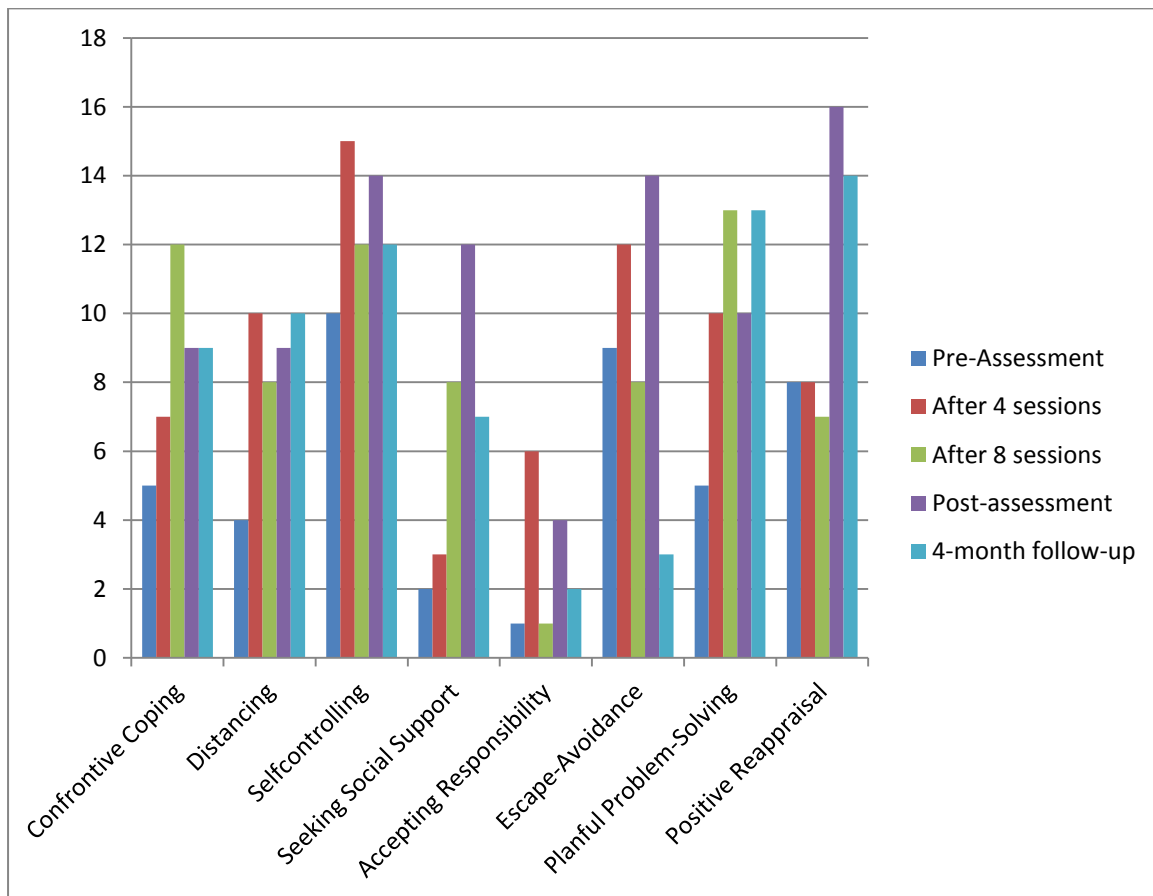


* The 4-month follow-up questionnaire was incomplete and subsequently not included in the graph

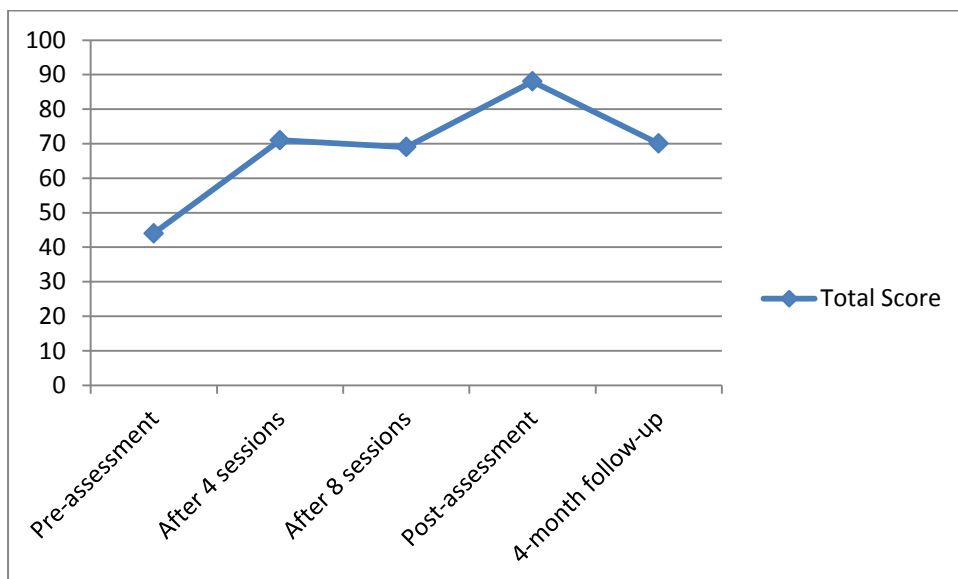
The Hope Scale



Ways of Coping Questionnaire: The Eight Ways of Coping



Ways of Coping Questionnaire: Total Score



3.1.7 Discussion

3.1.7.1 Psychotherapy's limited efficacy in lowering levels of parenting stress and depression

From psychometric results, the post-intervention interview and thematic analysis of all the sessions, psychotherapy appeared to have yielded modest gains at best. In fact, Patricia's mood and levels of anxiety and stress deteriorated during the middle part of therapy. As indicated by her 4-month follow-up scores, it was only after the introduction of pharmacology at the end of psychotherapy that Patricia's mood and levels of anxiety had started to improve appreciatively.

There are a number of possible explanations why psychotherapy failed to significantly attenuate the deleterious impact of depression and parental stress:

First, the establishment of rapport in the first session was not followed by the formation of a strong collaborative working relationship and sessions were at times stilted. I struggled to express my ideas succinctly and accurately at different intervals of intervention; I also stuttered at times; the extent of which I have not encountered before in my career as a psychologist.

It is possible that my performance as therapist was adversely affected by my apprehension about this being the first case study. It is also plausible that some of my feelings of fatigue and apprehension resembled countertransference feelings that calibrated with the high levels of anxiety and depression that Patricia had experienced at the time. Patricia described herself as being a constant worrier, always anxious, and sustained levels of anxiety were readily observed through the course of therapy.

Second, symptoms of generalised anxiety and depression are by themselves representative of complex and chronic psychological problems that might have lowered her amenability to psychotherapy.

Depressed parents are also more critical towards their children's behaviour than parents who are not depressed. They also tend to find it more difficult to manage their children's behaviour effectively (Neece & Baker, 2008; Reitman, Currier, & Stickle, 2002).

Third, the chronicity and severity of Sue's neuropsychiatric disorder and behavioural difficulties put considerable caregiving strain on a middle-class South African family with limited financial resources. The rendering of psychotherapeutic support did not negate the absence of a formalised behavioural management programme. Sue did not benefit from OT intervention; and her sheltered employment setting was understaffed and ill-equipped to manage her behaviour. Her appointments with consultant psychiatrists and neurologists were irregular because of long waiting lists and the chronic understaffing of medical specialists and mental health care professionals in the South Africa public health sector (Lund et al., 2010).

Last, as described in the narratives, Patricia's attributions of her psychological distress were initially firmly external (her stress was solely caused by Sue), invariant (there was little fluctuation over time and she had been stressed as long as she remembered) and global (Sue's behaviour affected all the areas of her life).

Psychometric assessment suggested that her parental locus of control remained firmly external; she also continued to report perceptions of helplessness with regard to the management of her daughter's behaviour.

It was only after anxiety was ameliorated through pharmacology that Patricia was able to lower her anxiety when dealing with Sue's behaviour. She told me at follow-up assessment that she was no longer *afraid* of Sue's behaviour. She effectively countered her fears by thinking about the outcomes of past episodes that were stressful but not life threatening. Moreover, she stated that she continued to employ the coping strategies she consolidated in therapy, which now led to more successful coping and the de-escalation of her parenting stress.

3.1.7.2 The increased use of coping strategies to deal with Sue's behaviour

Thematic analysis of the sessions and results from the Ways of Coping

Questionnaire suggested that some progress was made with reference to the other therapeutic goal: to use a wider variety of coping strategies more frequently in order to *try* and manage Sue's behaviour and other stressful life events more effectively.

The Ways of Coping Questionnaire measured a doubling in scores from baseline to post-intervention assessment. When completing the WAYS at various intervals of intervention, Patricia was asked to think about the manner in which she had tried to cope with a recent adverse caregiving event. Efforts to cope by employing different strategies could result in either effective or ineffective coping outcomes (Lazarus, 1999).

I am not suggesting that Patricia had more effective coping outcomes. Instead, by using a wider array of coping strategies, i.e., a greater number of coping "*instruments*" or "*tools*", I am tentatively proposing that her resilience to deal with caregiving adversity may improve over the long term.

The use of a wider array of coping strategies was generally maintained at 4-month follow-up. Of note, Patricia employed less escape-avoidance, i.e., wishful thinking

and behavioural efforts to escape or avoid the identified caregiving stressor (Folkman & Lazarus, 1988). It is possible that her improved mood led to less escape-avoidance. This strategy has been shown to be overrepresented among depressed mothers of children with ID (Woodman & Hauser-Cram, 2013).

A twofold increase in ratings which measured Distancing and Active Problem-Solving reflects Patricia's efforts to deal more effectively with Sue's behaviour. As I have described in the narratives, she engaged with her husband and children in trying to find solutions for how to manage her child's behaviour more effectively. She described her efforts to distance herself from distressing caregiving events as follows:

Patricia: . . . and I can walk away when Peter is trying to sort her out. I don't have to be there! I was always trying to be there to see if he's gonna be okay! It looks like he's gonna have a heart attack every minute . . . I walk away now. I walk away to the next room. I don't want to be there, and, uhm, it just makes things worse. One person can deal with it at a time.

3.2 The Second Case Study: Linda

3.2.1 Introduction

At the time of therapy, Linda was a fifty-two-year-old married woman with three children. Her eldest daughter, twenty-five-year-old Tony, had mild ID. Linda's other two daughters were twenty-three and fifteen years old.

Linda worked as a secretary for a large corporate bank and was often required to work over weekends and after hours.

Tony developed epilepsy when she was ten years old. She had at least two episodes of *status epilepticus*, a prolonged seizure. Up to that time, Tony was described as "a bright child" who had achieved her developmental milestones within age-appropriate levels.

Since the onset of her first tonic-clonic convulsions, Tony's seizures had never been well-controlled by the use of anti-epileptic drugs (AED), and according to neurologists and psychiatrists, her cognitive decline could be directly attributed to her epilepsy. Tony's cognitive decline had accelerated in the last three years.

According to her psychiatrist, the use of polytherapy, comprising a regimen of four AEDs, antipsychotic medication, and benzodiazepines, sedated Tony and had a negative impact on her ability to focus, attend and concentrate.

Tony's behavioural profile was characterised by daily episodes of verbal aggression. She also had erratic displays of physical aggression and property destruction. Her behaviour was superimposed on post-ictal psychosis and sustained irritability.

Tony's neurologist conceptualised her psychosis as an Axis I disorder. Tony also presented with depressed mood, and it was unclear whether her symptoms of

depression were the result of possible schizo-affective disorder or embedded in a neurological base that was associated with her epilepsy.

Linda reported elevated levels of parental stress that she attributed to her child's erratic aggression and psychosis. Whilst sub-clinical seizures had continued for many years, the majority of behavioural outbursts tended to occur at night. Linda reported chronic sleep-deprivation as a result.

Tony required assistance in completing most of her activities of daily living; she also had to be accompanied to regular specialist medical appointments. Linda was responsible for most of the household chores and tasks. Little time was left to pursue recreational activities, which left Linda exhausted at the end of most days.

In addition to stressful caregiving events, Linda reported the following stressors in her personal life:

First, Linda reported an acrimonious relationship with her husband who had struggled with alcohol addiction for more than three decades. She told me she had recently lodged an application at court to have her husband attend mandatory rehabilitation.

Second, as the sole breadwinner, Linda had to carry the family's financial burden. Her working environment was becoming increasingly taxing because of the corporation's rationalisation of staff and subsequent retrenchments. Linda stated that her workload had increased significantly as the result of the bank's efforts to enhance productivity with a smaller work force.

Last, Linda described considerable conflict with her youngest daughter. She stated that she felt guilty because so much of her time was allocated to Tony's caregiving.

Her youngest daughter had also complained at times that most of her mother's affection was reserved for Tony.

3.2.2 Case formulation

3.2.2.1 Predisposing factors

Linda recollected memories of early childhood as a time when she had felt disconnected and alienated from other family members. Her family of origin had discouraged the display of affection and Linda described her mother as reserved and aloof. She had subsequently spent much of her time on her own, this exacerbated by the fact that they lived in a semi-rural area that was some distance away from school. Her relative isolation made it difficult for her to socialise with her peers over weekends.

Described as a stoic individual, Linda's grandfather was the only member of her extended family who had displayed some affection towards her by singling her out and spoiling her with edible treats. There was a discernible tremor in Linda's voice when she recalled an incident when her grandfather bought her a doll for Christmas. Her grandmother's condemnation of her spouse's indulgence in the face of financial hardship did not detract from Linda's positive memories.

Her grandfather was murdered when she was ten. As a formative influence, Linda therefore lost the only adult who had displayed affection towards her. Throughout the course of therapy, Linda repeatedly stated that loved ones could be taken away from you unexpectedly. She linked this belief with her reluctance to display too much affection towards her daughters, believing that emotional intimacy would predispose her to greater emotional pain should her loved ones pass away. I believe that her grandfather's death was a formative experience predisposing her to these

beliefs. Linda also stated that her problems with the display of emotions could be traced back to her parents' lack of emotional displays of affection.

Later on in her life, the onset of Tony's epilepsy and repeated episodes of *status epilepticus* reinforced the idea that as a mother she was vulnerable to loss and emotional pain. On a psychodynamic level, an internal phantasy world of annihilation and death-taking found external expression in the objective situation each time that Linda had witnessed her child's seizures.

3.3.2.2 Precipitating factors

Linda told me that her parental stress had become persistently elevated from the time that Tony had developed epilepsy. She also stated that her parental stress became more pronounced after Tony had developed psychosis in her twenties. Linda traced the onset of depression back to her earlier years of marriage and her husband's failure to manage his addiction. Persistent financial worries were also described as ongoing stressors. Other stressful life events included the following:

First, her elderly parents, who provided most of Tony's caregiving when Linda was working, had recently applied for placement in a retirement home. Linda was worried how this would impact on Tony's caregiving. Second, her initiative to obtain an interdict to have her husband receive mandatory treatment for alcohol addiction involved the stressful process of attending court. Last, Linda was physically exhausted and felt emotionally depleted because of her workload and required overtime responsibilities at the bank.

3.3.2.3 Maintaining factors

Linda developed a number of parental coping strategies to fortify herself against the negative emotional impact of Tony's behavioural difficulties, epilepsy, and cognitive

decline. The habitual reference of herself in the third person suggested the use of mental disengagement or escape-avoidance, which resonated with baseline scores on the Ways of Coping Questionnaire. I noted that Linda often used humour or changed the subject when painful or distressing parenting events or other stressors were discussed in therapy. On a behavioural level, I believe that Linda's extra hours at work served an additional purpose because she was able to avoid home. For the same reason, Linda went out during weekends and spent the rest of her time sleeping.

Linda described feelings of anger and a sense of helplessness about her financial hardship and the lack of caregiving support that she had received from relatives and formal services.

3.2.3 Narratives of psychotherapy sessions

Session one

A psychiatric interview was conducted to obtain information about Linda's personal history and applicable background information about previous and contemporary psychological problems.

She described her upbringing in a conservative Afrikaner home in the predominantly English-speaking Southern Suburbs of Cape Town. As reported previously, Linda felt disconnected from her family:

Linda: So I was on the outside. Uhm, I got up in the morning; I had my breakfast; at High School. . . I'm . . . I put in my own lunch; walked to the bus station; went to school; came back; had something to eat; went to my room; did my homework; came out for supper. I didn't really mix or feel in [sic] with them.

Besides her longstanding sense of disconnection and a lack of family support from her eldest daughter, husband and two brothers, Linda attributed her emotional distress solely to Tony's epilepsy, behavioural problems and intellectual disability:

Linda: And it's all because of Tony's illness! (crying) I've built this wall around me, uhm, to protect myself. And if I show emotion to others, it's gonna make me feel, uhm . . . (long pause) . . . weak. Uhm, that I'm not gonna cope. If I'm weak, I won't be able to cope and I'm gonna break! So I have to build this wall around me to keep myself strong!

Linda was tearful throughout the session. She described a number of symptoms of depression, including the following:

- Depressed mood.
- Helplessness and hopelessness.
- Pervasive feelings of fatigue and low levels of energy.
- Weight gain and over-eating.
- Difficulty in sustaining her concentration and attention at work.
- Excessive feelings of guilt towards Kim because of the amount of time she had to spend on Tony's caregiving tasks.
- Sleeping problems, albeit that Tony's night time disturbances continued to interrupt her sleeping patterns.
- Previous suicidality.

Although Linda was initially reluctant to acknowledge that she felt depressed, she openly disclosed longstanding feelings of sadness and fatigue after psychoeducation had focused on the symptoms of depression. We also discussed her BDI-II results, which were consistent with clinical observation and placed her in the severe range of

depression. She elaborated on how difficult it was for her to cope with all her responsibilities and family circumstances at home. Her worry about Tony's deteriorating health also added to her sense of helplessness and hopelessness:

Linda: (sighs heavily) (15 second silence) Ah, I feel hopeless when. . . Well, hopeless and helpless is the same thing when . . . especially when Tony goes into the seizures. She falls; she's on the floor just staring at you with those big, round eyes. Uhm, there is nothing that you can do. And until the seizure's over. . . And sometimes it is, as I said, it goes up to an hour.

Linda appeared frustrated and angry towards medical professionals. She told me at different intervals that she received little support from healthcare:

Excerpt 1

Linda: They promise a lot of things but they don't do anything.

Excerpt 2:

Linda: Uhm, there's no other real advice. Because people don't know how to treat her.

Excerpt 3:

Linda: All they tell me is: "*Put her into a psychiatric place!*" I've done that and it didn't work. And she's now back at home.

Based on the available background information and our discussion, the following therapeutic goals were formulated:

First, to significantly decrease parental stress; second, to improve her mood and low energy levels in particular. Linda also agreed to engage in more enjoyable activities

such as reading and more regular social outings with two of her friends. While she often left home during weekends, most of the time she visited shopping centres and malls on her own.

Third, we also agreed to fortify her coping strategies and management of Tony's behaviour.

Last, we also concurred that Linda was left with unfinished business about the development of Tony's epilepsy in middle childhood. Linda shared how difficult it was to come to grips with the loss of a healthy child:

Linda: Uhm, I still can't accept it. Uhm, seeing Tony from being a healthy child turning into the state that she is today isn't easy to accept. Tony slowly deteriorated. It's not . . . how can you say it? It was slowly going downhill. Uhm, when she went to ** [special school's name], I actually felt guilty for sending her away . . .

Session two

Symptom checks for depression and fatigue remained elevated at 80 and 90 respectively; and BDI-II scores continued to rank in the severe range of depression. I requested that we discuss the CBT model and Linda put her recent conflict with her youngest child on the agenda. Linda successfully completed a 3-column Dysfunctional Thought Record as a homework exercise. Behavioural activation also yielded results and Linda reported that she had started reading romantic fiction as agreed upon in the first session.

Her youngest daughter, Kim, told her that she wanted to experiment with alcohol and tobacco smoking. When Linda voiced her disapproval, Kim accused her of being

negative. Linda was also accused of taking sides by allowing Tony to “*behave badly*” without instituting consequences. In an angry tone of voice, Linda stated that Kim “*blamed me for everything that goes wrong*”. She also told me that she felt useless as a parent.

While Linda often coped with conflict by confronting Kim, at other times she distanced herself and tried to control her anger:

Linda: . . . but I know if I’m gonna keep on arguing with her it’s gonna be a big, big argument. And it ending up with both of us shouting and screaming at each other. So I rather keep quiet; keep my distance, but she’s not always happy with it. And I know they say you mustn’t go sleep angry, but ja . . .
(Sighs)

With her husband’s alcoholism in mind, Linda was worried that her youngest child would also become dependent on substances:

Linda: Because I’ve seen the evidence...

OC: [cross talk] Where?

Linda: I know what it can do!

OC: Where did you see it?

Linda: With my husband!

We identified and discussed Linda’s negative automatic belief of being a “*useless*” parent. Linda realised that she was trying to protect Kim by opposing her intentions to experiment with substances. She was therefore able to modify her beliefs to “a concerned parent”.

Psychoeducation focused on the clinical symptoms of depression. We decided that Linda should complete a 4-column DTR as her next homework assignment.

Session three

Linda arrived fifteen minutes late for the session. Symptom checks for depression remained elevated at 70 although BDI-II scores suggested that she felt less depressed. When I asked about her mood, Linda stated she was feeling less depressed and a bit more hopeful about the future. She remained exhausted and rated her fatigue at a maximum score of 100.

She became tearful whilst describing another conflictual situation with her youngest daughter and we decided to put the item on the agenda. Their disagreement stemmed from Linda's refusal to allow Kim to visit Linda's second eldest daughter, Rita. Linda thought that Rita was disrespectful towards her after her second eldest child contacted Kim to arrange a visit without consulting with Linda:

Linda: I'm the one with the car, not Kim! Yeah, but she was under the impression that Kim would tell me. But I don't take words from Kim! I said no, because I've considered them! So sometimes she also now speaks down to me! (Emotion clearly discernible in voice). She doesn't respect me as a parent!

Kim then started blaming her mother and conflict escalated. Linda eventually slapped her daughter. She avoided her children through the course of the next two days. Linda described feelings of anger, guilt and regret for having lost her "*nerves*" and for being irritable; she also perceived Kim's acting out behaviour as reflecting low levels of parental competence:

Linda: (Sighs) Well, I felt bad . . . as a bad mother . . . I failed as a mother, because, uhm, if this is the type of child I've been raising . . .

OC: Mm.

Linda: . . . then I wasn't very good at it! Uhm, she made me feel worthless

Overgeneralisations and selective abstractions implied that she perceived her relationship with Kim as being continuously conflictual. She also had imperative thoughts that she should have exerted more control over the situation. As opposed to Linda's belief that she was an inadequate and bad parent because she lost control, we sought alternative explanations for her irritability:

- Of late, Tony was experiencing visual hallucinations and delusions at night; and Linda was getting by with less than five hours of sleep.
- Her working life was especially stressful at the time; and Linda worked for ten hours per day.
- She was also angry with her children, husband and relatives for not supporting her with Tony's caregiving.
- She told me that she was experiencing financial strain. She blamed her husband for not contributing financially to cover household expenses.

Because of Linda's state of exhaustion, we agreed that she should apply for respite services to allow her a break from ongoing caregiving demands. Based on Tony's behaviour at the time, admission into hospital was also warranted. We discussed the process of admitting Tony via the district hospital system and 72-hour observation period. The idea of placing Tony in an agency's care activated self-blame and guilt:

Linda: (long pause) (sighs) Ja! I am passing on my responsibility again! I want to get rid of her, which in a way I am. (Sighs heavily and starts crying.)

Session four

For the first time, Linda decided to have Tony admitted to a district hospital following an episode of verbal and physical aggression that was directed towards her second eldest child. Tony was subsequently transferred to an acute psychiatric ward for adults who have ID. She reported that her mood has improved following Tony's admission – her self-rating scale for depression improved from 70 to 50. BDI-II scores remained in the moderate range of depression, markedly lower than scores from assessments during the first two sessions. Her self-rating of fatigue also came down slightly but remained elevated at 80.

Linda voiced her unhappiness about the long waiting time in the Emergency Room of the district hospital. She also doubted whether the doctors believed her about Tony's aggression, because her daughter had calmed down by the time they arrived at hospital:

Linda: Yeah, but then why do I have to feel that I'm begging for assistance? Why couldn't they just accepted my word and – and admit her the first time?

Basic behavioural rehearsal anticipated a similar scenario in future. We agreed that it would be useful to provide more comprehensive information about Tony's diagnoses, which would in turn elicit the complex behavioural support needs of her daughter. I was hoping that the disclosure of information in a concise and factual manner would allow a more efficient response from hospital staff.

We also briefly discussed an incident that occurred earlier in the week. Linda described feelings of extreme anger towards her husband after he had taken meat out of the fridge without informing her.

She also requested a meeting with her in-laws to seek their support in placing her husband in an Old Age Home because of his substance dependence. Linda had little hope his family would abide by her plans, but felt better after she had demonstrated her unhappiness about the current state of affairs to his sisters.

Session five

Linda's symptom checks of depression improved from 50 to 10 and BDI-II scores now ranked in the mild range of depression. She continued to give high ratings to fatigue (75). Psychometric assessment following the fourth session suggested that high levels of parental stress came down from a baseline of 164 to 104 (PSI-SF).

Linda started the session by describing her ongoing conflict and anger towards her husband. She stated that the only reason she stayed with him was to be entitled to the proceeds of sale of the estate. This was in accordance with the conditions that were specified by his late parents' last will and testament. The following excerpt gives an idea of the animosity and anger which had persisted between them over many years:

Linda: He's threatened to slash my tyres; he's threatened to burn my car out. Now he's threatened to change the locks. He wants the key to the safe so he can get the gun. What he wants to do with it I don't know. If it is for suicide then I'll let him have it! But I don't have the key; his sister's got the key!

Linda became tearful and distressed during the last fifteen minutes of the session. Psychotherapy therefore continued after its allotted time to ensure that Linda did not leave the session in an agitated state.

As a homework assignment, I requested that Linda compile a list of reasons why she blamed herself for having Tony admitted to hospital. She also had to write down counterarguments why she should not have felt guilty. Linda provided the following evidence to validate her feelings of guilt: Tony appeared lost and her daughter was crying; she also believed that she was abandoning her child. Her counterargument was contained in a brief statement that Tony would receive better care in a psychiatric unit.

Compared with her relatively detailed DTRs in previous homework assignments, her vague statements in this exercise invited further exploration. I therefore requested that we discuss her feelings of guilt and self-blame as an agenda item. Linda did not add items to the agenda. The session became stilted after Linda again pondered whether the nurses and doctors believed her descriptions of Tony's aggression.

I observed a mood shift when I asked Linda how long she had felt guilty towards Tony. Linda became visibly emotional when she started to describe different possible reasons why Tony developed epilepsy and intellectual disability:

Linda: But I don't know. It could be, uhm . . . when Tony was about six months old, he (her husband) was also drinking hectic. And he wanted the car keys, and I told him I don't have it. It was on the stoep (porch), on the bench where he put it himself. But when he slapped me, Tony's head knocked against the wall. Okay, it wasn't that hard. So I can't think that that had something to do with it. I don't know, because your skull is rather

thick . . . to protect that. Then she had a second knock when she was a child. He was busy hitting something for the tyres, for the wheel, whatever. And she was also always very inquisitive. And as he knocked . . . (inaudible segment) No. Ja, she looked down as he came up for the next. . . . So her whole eyebrow was open! We had to get four or five stitches. And once as well, when she was smaller . . . she got, she climbed onto the counter, and she fell off and she had this big bump there.

Linda told me neurologists had repeatedly assured her that Tony's epilepsy was hereditary, and I also noted that these events occurred during infancy. Tony's epilepsy only started in middle childhood. Yet it is possible that Linda's descriptions of these events as potential causes of her daughter's epilepsy pointed to beliefs that she was to blame for her daughter's medical illness and disability. More specifically, I conceptualised the possibility that Linda felt guilty for leaving her infant daughter in the care of an intoxicated husband.

Session six

Linda rated her mood at 50, higher than her previous score of 10. BDI-II scores continued to measure mild depression. Symptom checks of fatigue came down from 75 to 60.

She requested that we discuss her youngest daughter's subject choices for her last three years in school. I suggested that we also continue our discussion of last week about her feelings of guilt and self-blame, specifically regarding the earlier parenting events that Linda linked with the possible development of her daughter's epilepsy.

After discussing Kim's subject choices, the introduction of our second agenda item led to an immediate change in Linda's non-verbal behaviour: she became tearful and visibly distressed when she told me that she realised she was not to blame for Tony's epilepsy. Yet she continued to feel saddened by the loss of a healthy child. Linda subsequently labelled her child with specific beliefs and emotions:

OC: . . . if Tony is sad, what could be the possible reasons for that?

Linda: She knows she's different.

OC: Yes?

Linda: She knows she's not at home. (Metaphorically alluding to intellectual disability)

OC: Ja?

Linda: She knows we don . . . she doesn't fit in anywhere; she's not welcome anywhere or everywhere. Uhm, she knows that she can't do the things that she used to do.

OC: Ja – loss . . .

Linda: What is the meaning of life? If you have to be like a vegetable! (Long pause)

Linda's unfavourable depiction of her daughter as a vegetable stood in contrast to another statement in the same excerpt, implying that her child was acutely aware of her deteriorated adaptive abilities (*"she knows she can't do the things she used to do"*). At a minimum it appeared as if Linda's statements did not fully consider the complexity of her child's neurobiological, psychiatric and developmental profile. I

therefore provided basic psycho-education about diagnostic overshadowing and gently challenged Linda to consider the possibility that Tony had some insight about her cognitive decline, and the myriad social challenges she was facing. Far from being in a vegetative state, Tony was in fact known to the service as a resilient person.

Linda also stated that she felt guilty whenever she pursued her own interests:

Linda: How can I enjoy myself knowing my child is unhappy? (starts crying)

Imperative thoughts reflected self-imposed rules that Tony must always accompany her when she went out. We briefly discussed the need to have respite opportunities and ways of engaging with Tony to maintain appropriate boundaries.

Similar to previous sessions, Linda blamed herself for being angry and irritable towards her other children. At first she attributed her irritability to the demands of Tony's caregiving. However, once we started exploring other dynamics, Linda identified other stressors, including her conflict with her husband and youngest daughter as well as her constant worrying about crime and their safety on their small holding.

Session seven

Linda's symptom checks for depression ranked higher at 80 and BDI-II scores measured moderate depression. She gave a maximum rating for fatigue.

According to Linda, her mood deteriorated after Tony was discharged for the weekend on a home visit. Linda also experienced stress at work because the bank's computer network had been offline for three days. Yet when I asked Linda to draw a

pie chart to proportionate the role of both stressors, Linda attributed all her distress to Tony.

Linda had a negative automatic image of Tony while we were discussing her daughter's epilepsy and cognitive decline:

OC: . . . when you were sitting here now and you started to get a bit sad, what were you thinking about; what made you . . . (Pause) Did you see an image that made you sad?

Linda: I just see that poor child! (tremor in voice, starts crying)

OC: Yeah?

Linda: (sighs heavily) It doesn't look good! (inaudible segment, crying) It doesn't look like she's gonna become any better! And I'm just dreading the day that they phone me to say she's being discharged. What am I gonna do? (sighs heavily)

I asked Linda what she would do if Tony was discharged:

OC: If Tony is discharged, what will happen?

Linda: Where will she go to? I don't want her! I can't anymore!

I subsequently asked Linda to brainstorm possible ways of managing Tony's potential discharge from hospital. She was increasingly reluctant to leave her child in the care of her elderly parents during the day. Linda also briefly thought about locking Tony up at home, but dismissed the idea almost immediately. She considered the possibility of refusing to fetch Tony from hospital. When I suggested

that we consider the possibility of community-based residential placement, Linda rightfully pointed out that her previous attempts to place her child were unsuccessful.

It was apparent that Linda's parental stress and helplessness related to more than Tony's behavioural difficulties, epilepsy, cognitive decline and emotional well-being. Her reluctance to have Tony back at home added to her distress and helplessness, especially because alternative placement options were not available.

In an angry tone of voice, Linda stated that health care professionals did not believe her when she told them about Tony's aggression at home and how difficult it was to manage her child's behaviour. She asked me if she could go and fetch something in her car. She then produced a printout in which epilepsy is basically described as a form of pathological attention-seeking and faking. When I pointed to the neurobiological and disability-related factors of Tony's problem behaviours, Linda insisted that Tony had control over her behaviour.

When asked how she coped with the worry and rumination that were activated and maintained by persistent uncertainty and parental stress, Linda responded as follows:

Linda: I just go blank and push it out of my head.

OC: Okay. You distract yourself. Distraction is a possibility. Does it help?

Linda: No.

OC: Okay, why doesn't it help?

Linda: It doesn't take it away, the-the . . . (sighs heavily) (pause) Although you try and forget about it, uhm, it eats on you on the inside.

OC: Mm. Mm.

Linda: And although there's physically or . . . there's nothing wrong, but I can feel inside, emotionally. . . (sighs heavily, tremor in voice, tearful and crying)

Metacognitive strategies were used to try and break the physiological arousal that was maintained by rumination and worry. Linda identified internal and external triggers that led to heightened arousal: spontaneous thoughts about Tony's cognitive decline; and similar reactions of distress and despair were triggered when colleagues at work asked her how Tony was. We then used imagery to simulate a recent event when a colleague asked her about Tony's well-being. Linda was instructed to first become aware and acknowledge her distress through self-talk, e.g., this is upsetting me because Tony is not doing well. The second instruction was to regulate her breathing and again acknowledge both Tony's deterioration and her own helplessness to prevent it. The last step was a deliberate decision to self-regulate by distracting herself through engaging in purposeful behaviour. Concurrent self-talk recognised the futility of worrying about something over which she could exert little control. She was also asked to acknowledge the negative and unpleasant impact of emotional arousal, which in turn necessitated the need to deliberately distract herself in order to lower arousal levels.

Session eight

Linda's BDI-II scores came down from moderate to minimal depression and her symptom checks for depression and fatigue came down to 40 and 50. She told me that she started reading late into the night, a positive development that she attributed directly to psychotherapy.

Linda provided feedback about an earlier session that covered her youngest daughter's subject selection. She also indicated that her relationship with Kim had improved:

Linda: Uhm, at the moment it's fine. We haven't had major arguments.

Linda told me that she now saw Kim's constant bickering with Tony as the result of intense sibling rivalry that stemmed from the extra attention that Tony required because of her disability.

Although Linda became tearful and sad while we were discussing Tony's cognitive decline and frail physical health, unlike previous sessions she did not try to change the topic. She discussed the emotional impact of Tony's deteriorating health on her as a parent, albeit in the third person:

Linda: (Tearful) Uhm, well there's a difference. If she was to die, then you get mourn and you know, okay, she won't come back. But now she is still there; she's still alive . . . but you're still mourning.

OC: Tony?

Linda: So it doesn't look like it's gonna end! If she's died and . . . eventually it will . . . you still remember her, uhm, but the pain will subside. But now you can't because it will always be there until she dies. Or I die before, I don't know. It's normally supposed to be the parents to go first, but in her case, I don't know how long she's gonna live. I've got no guarantees she's gonna outlive me!

Linda recalled a meeting with medical professionals to discuss surrogate decision-making should extensive brain-damage result from a prolonged seizure:

Linda: To decide how far must they go . . . (increased volume) It's not my choice! I don't want to make that choice! Let her go or keep her alive! Maybe for her it would be better to let her go, but will I be able to live with my conscience if I make that decision? I don't know.

While Tony's admission into hospital offered a temporary respite from caregiving stressors, Linda's helplessness, hopelessness and negative emotions such as sadness and anger were maintained by persistent rumination and worry. The fact that Tony's deterioration was confirmed by specialists validated an external locus of control to some extent.

At work, the mere mentioning of Tony's name was enough to evoke strong emotional reactions. We therefore continued to use metacognitive strategies to try and break patterns of physiological arousal.

Session nine

Linda assigned ratings of 30 for depression and 45 for fatigue; her BDI-II scores also continued to measure in the range of minimal depression. Comprehensive psychometric assessment, conducted after Linda had completed her eighth session, measured significantly lower levels of parental stress and gains with regard to levels of parental competence and satisfaction.

Tony was visiting home each weekend and sometimes only returned to hospital on Tuesdays. In part, Linda attributed her improved mood and lower levels of parental stress to Tony's admission and the caregiving respite that hospitalisation offered. She also reported that it was less distressing to respond to enquiries from others about Tony's physical and mental well-being.

Following the last session, Linda started monitoring her emotional reactions to such questions in a somewhat idiosyncratic fashion by using imagery of my frowning face when she became aware of her distress. She then acknowledged her emotions and tried to distract herself. Although she said it was still easier to ignore her feelings, she also stated that her strategy worked – she did not cry once about Tony's problems during the course of the last week.

Tony's psychosis was unremitting and a cryptogenic diet was introduced as another measure to try and control her epilepsy. I wanted to discuss a risk mitigation plan with Linda because of the continued risk that Tony's aggression posed to herself and family members. I also thought that Linda's agency and perceived control would be enhanced if she had strategies to deal with risk following Tony's discharge.

In previous sessions, Linda complained about the lack of responsiveness from various medical professionals. She was also unhappy about the frequent medication changes. I provided information about legitimate recourses to voice her concern about Tony's mental health problems, treatment and clinical risk. Linda passively listened to suggestions of accessing the support of the Provincial Mental Health Review Board and the possibility of arranging a case conference through hospital structures to discuss Tony's high behavioural and medical support needs.

When I subsequently asked her what she would do if she received a phone call from the hospital informing her that her child was about to be discharged, Linda became visibly irritated and told me that she would phone me or "*camp*" next to my office. Other attempts to enhance her agency by describing pathways were met with similar responses and devaluation:

OC: And if you have certain concerns about the quality of care, who do you approach to raise those concerns? Do you know, Linda?

Linda: My first thought is: "*Bel vir OC!*" (Phone OC)

OC: Ja?

Linda: Maar OC weet nie alles nie. (But OC does not know everything.)

Linda's mood and parental stress had improved significantly from baseline and we discussed possible termination after the previous session. We therefore agreed that the next session would be the last. On a conceptual level, I tentatively linked Linda's anger towards me with possible termination issues regarding abandonment. I did not raise the matter in our sessions and the countertransference reaction was used to regulate my own behaviour through ongoing efforts to be supportive and containing.

Session ten

Symptom checks for depression and fatigue remained unchanged at 30 and 45 respectively. Linda's BDI-II score of 9 fell in the range of minimal depression.

Discussion focussed on the following: Linda provided feedback about her experience of psychotherapy:

Linda: No, I found it very helpful. Uhm, I can now understand better what is going on with Tony and her circumstances. I don't feel that guilty anymore.

OC: Excellent.

Linda: Uhm, I don't feel that . . . uhm . . . (pause) . . . that everything is my fault. I know there is people who also try to take care of her; that it's not only

my responsibility at the moment, thank you. But ja! I am more relaxed, uhm, as I told you, even my own daughter said: *"You look a bit more stress-free."*

Uhm, I still feel sorry for my child.

The role of earlier, formative parental experiences on Linda's contemporary beliefs and emotions was again highlighted. More specifically, we briefly discussed the distressing time when Tony had developed epilepsy, which I believe led to the subsequent formation of fundamental parental core beliefs that she was to blame for her daughter's epilepsy and generally her child's unhappiness and distress. Linda also stated that she felt guilty for sending her child to a boarding school, away from home:

Linda: Uhm, well I had a very low self-esteem at the time. Uhm, I felt helpless, worthless; I did something wrong . . . It was my fault that she was like that.

OC: Thoughts, yes.

Linda: I probably did something wrong in all my previous lives that I'm getting it now. Uhm, ja I just didn't have any happy thoughts at the time! It was all negative.

We also discussed some of the persistent caregiving demands which continued to challenge Linda's ability to cope and remain resilient. Linda had to come to grips with her child's progressive cognitive decline; and Tony was also increasingly frail.

As described earlier, we covered Linda's worry and apprehension of her child's deterioration by focusing on metacognitive strategies to try and mitigate the impact of intrusive thoughts and images of her child's frailty and emotional problems:

Linda: Ja, whenever I think of Tony, when I get flashes of her, I just: *“Shame, poor child! Uhm, I wonder what she’s doing now, but okay, what’s next?”*

We also focused on the inadequate support that she received from relatives, and her husband’s lack of support. It was important to plan ahead because her parents would soon not be able to provide caregiving during the day when Linda was at work.

3.2.4 Interview after psychotherapy had been terminated

Linda provided positive feedback about psychotherapy and reported that she felt less depressed and guilty about past events. She indicated that she was able to work through many of the unresolved issues regarding Tony’s development of epilepsy, which left her with a sense of loss and grief. She also felt less guilty when enjoying activities without Tony being present.

Linda told me that she benefited from the “learning experience”; she understood Tony’s behaviour better after we had covered symptoms of psychosis as part of psychoeducation. I believe that Linda developed a more balanced view of Tony’s behaviour as the complex result of neurological and environmental instigators.

As Linda’s guilt towards Kim lessened, she was able to become more assertive by holding her youngest child to account in assisting her with daily chores at home:

Linda: Yes! I am not a bad mother. Uhm . . . (pause) I’m not that helpless or hopeless anymore . . . from what I used to be. Uhm . . . at least I can . . . I can make a . . . a decision without interference of anybody else or have the help of anybody else. I am firmer with Kim where I used to just let it go. Do your own thing to avoid problems. But . . . I’ve grown!

3.2.5 Themes that emerged from thematic analysis

As with Patricia and the other case studies, there was overlap between different themes. For example, Tony's behavioural outbursts sometimes led to different emotions such as distress, sadness, anger and guilt. The loss of a healthy child was thematically linked with rumination and worry, but it was also linked with the onset of Tony's epilepsy, a formative influence to contemporary guilt. Linda's cognitive distortions were evident in different situations, including when she worried about Tony's deterioration or during conflict with Kim. I therefore tried to formulate themes into categories because of the conceptual differences between constructs that also at times showed overlap. For example, maternal anger is a different emotion from sadness and guilt even when both were at times triggered by similar events.

Theme	Excerpt
Parental stress that was brought upon by Tony's aggression and high medical as well as behavioural support needs	<p>Linda: Very bad! Uhm, especially my parents. Uhm, as you know they're both old. She's threatened to hit granny with her fist. They can't defend themselves.</p> <p>OC: They're frail now?</p> <p>Linda: What do you do? Especially when she's psychotic, she's so . . . extremely strong.</p> <p>— Linda: Uhm, but sometimes it does help, especially when I wake up at night and she's standing over me with a knife: <i>"I'm gonna kill you!"</i> I just look at her. And when she eventually puts the knife down. Uhm, the other night she had me around the throat.</p>
Maternal depression and perceptions of helplessness	<p>Linda: You try your best but it doesn't seem to always help. You feel helpless.</p> <p>— Linda: Then why isn't there medically something that they can do? Tony's been on every single medication that there is on the market! They've tried everything! The cryptogenic diet didn't work! The induced coma didn't work! The medication didn't work! What else is left? Cut out her brain and put in a new one . . . if it was possible</p> <p>— Linda: I don't . . . I feel annoyed, I feel . . . helpless. I don't want to go home. Because all that waits for me there is problems. I just wish I can get in my car and drive off! And never come back. (crying) But it's not gonna solve the problem!</p>
"I am a bad mother": Guilt, self-blame and hopelessness as symptoms of maternal depression.	<p>Linda: (Sighs) Well, I felt bad . . . as a bad mother . . . I failed as a mother, because, uhm, if this is the type of child I've been raising . . .</p> <p>— Linda: (3 second pause) There is something wrong with it. Uhm, I can't tell her what to do; she doesn't listen. She always wants to have the last word. I know that I'm not strict enough with her. So it makes me a bad mother, because I</p>

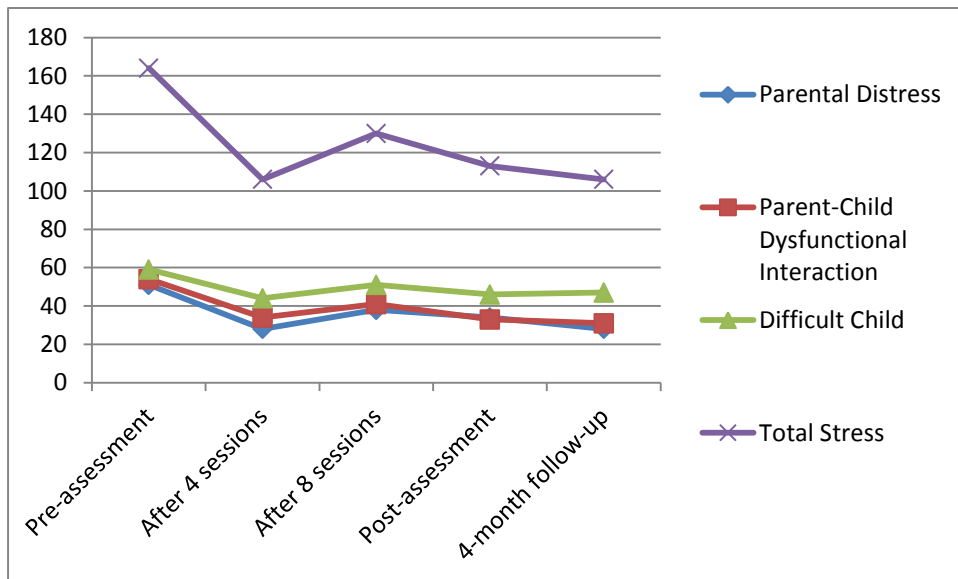
	can't be consequent [sic].
Formative influences from childhood and early parental experiences	<p>Linda: So I was on the outside. Uhm, I got up in the morning; I had my breakfast; at High School I'm . . . I put in my own lunch; walked to the bus station; went to school; came back; had something to eat; went to my room; did my homework; came out for supper. I didn't really mix or feel in [sic] with them.</p> <p>— Linda: Uhm, I still can't accept it. Uhm, seeing Tony from being a healthy child turning into the state that she is today isn't easy to accept. Tony slowly deteriorated. It's not . . . how can you say it? It was slowly going downhill. Uhm, when she went to ** [special school's name], I actually felt guilty for sending her away.</p>
Stress, anger, frustration, resentment and ambivalence towards other family members	<p>Linda: I know: shouting back at her; screaming; yelling at her. At that moment it makes me feel better, but afterwards you feel bad!</p> <p>— Linda: I'm the one with the car, not Kim! Yeah, but she was under the impression that Kim would tell me. But I don't take words from Kim! . . . she doesn't respect me as a parent!</p>
Coping with caregiving challenges through escape-avoidance and wishes to abandon caregiving responsibilities	Linda: Where will she go to? I don't want her! I can't anymore!
<u>Cognitive variables</u>	
<i>Attributions of globality/overgeneralisation</i>	Linda: And it's all because of Tony's illness! (crying) I've built this wall around me, uhm, to protect myself. And if I show emotion to others, it's gonna make me feel, uhm . . . (long pause) . . . weak. Uhm, that I'm not gonna cope.
<i>Attributions of intentionality</i>	Linda: You can't take her anywhere. It has an effect on the other children in the house. Tony became very aggressive; she wants her own way! She's very manipulative, uhm, once you . . . (sighs) Well, to keep her calm you have to give in.
<i>Cognitive errors: all-or-nothing thinking</i>	Linda: There is no help, there's no assistance, nothing whatsoever!

	<p>— Linda: They promise a lot of things but they don't do anything.</p>
Accepting responsibility and confrontive coping to keep the peace	<p>Linda: To keep the peace! I want to have the last say why must I keep my mouth or stop doing what I'm doing just because of her! So it did have a big impact. Uhm, she's a . . . (crying) What you call it? Uhm, '<i>n verleentheid</i>? (an embarrassment)</p>
Stigma	<p>Linda: The other kids' friends, uhm, you never know how she's going to react. So a lot of people, they don't understand the situation.</p> <p>OC: Ja. Ja.</p> <p>Linda: So you're not always welcome everywhere.</p>
Lacking coping resources: Inadequate formal and family support	<p>Linda: Uhm, there's no other real advice. Because people don't know how to treat her.</p> <p>— Linda: All they tell me is: "<i>Put her into a psychiatric place!</i>" I've done that and it didn't work. And she's now back at home.</p> <p>— Linda: Uhm, there is no real support except from my mother whose got no choice.</p> <p>OC: Ja?</p> <p>Linda: Uhm, unfortunately my brother stays far. Well, they stay in the Northern Suburbs. Both them and their wives are working. So there is no really support from their behide [sic] . . . besides: "<i>How is Tony?</i>" The normal questions. Uhm, from the other side of the family, they're not interested because they can't accept her. Or, they don't want to get involved in her behaviour. Uhm, they can't handle it.</p>
Constant vigilance	<p>Linda: So you have to be careful all the time around her of what you say, what you do, what your actions are, even if you don't speak to her! You're speaking to somebody else. She'll see it as an</p>

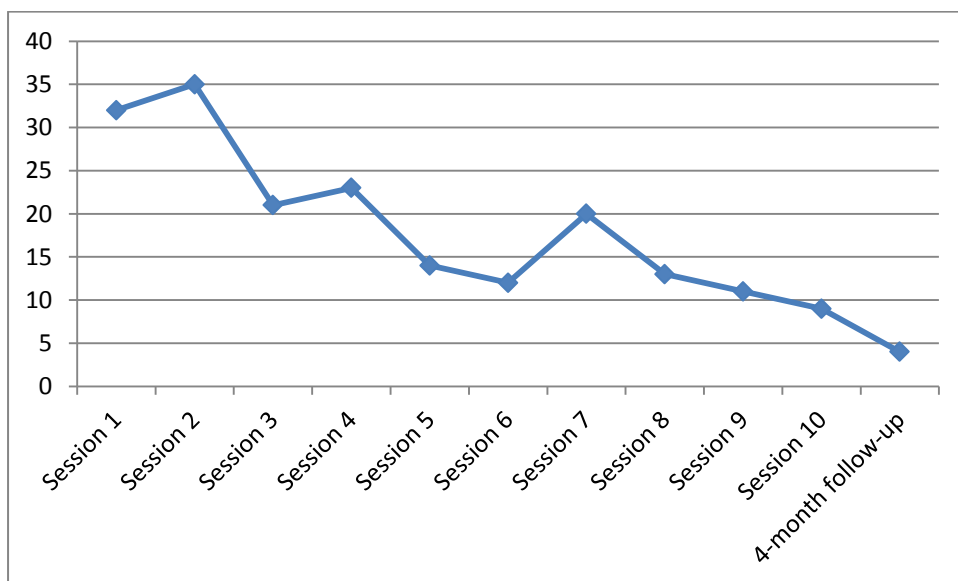
	<p>attack on her . . . so it's stressful to live like that. I'm tensed up all the time!</p>
Financial concerns	<p>Linda: A lot, especially since he's been unemployed for the last . . . what is it now, four years? (Sniffs) Uhm, I'm the sole bread winner.</p> <p>OC: Mm.</p> <p>Linda: Uhm, I can't always make ends meet. And to sit with – with Tony and him . . . I can't!</p>
Rumination and worry: The loss of a healthy child	<p>Linda: It's like mourning. But this mourning doesn't stop! . . . it's just carrying on. It's loss, bereavement.</p> <p>Linda: Uhm, I still can't accept it. Uhm, seeing Tony from being a healthy child turning into the state that she is today isn't easy to accept. Tony slowly deteriorated. It's not... how can you say it? It was slowly going downhill.</p>

3.2.6 Psychometric test results

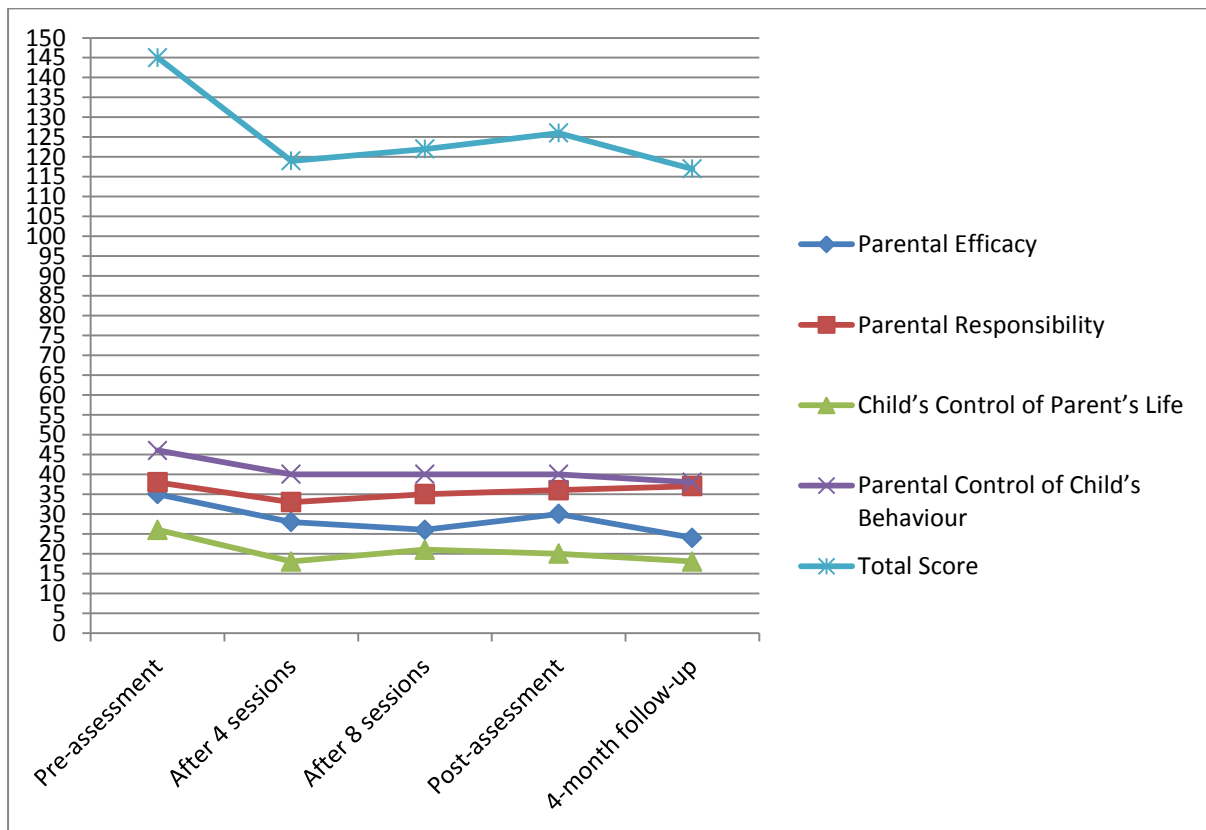
The Parental Stress Index: Short-Form (PSI-SF)



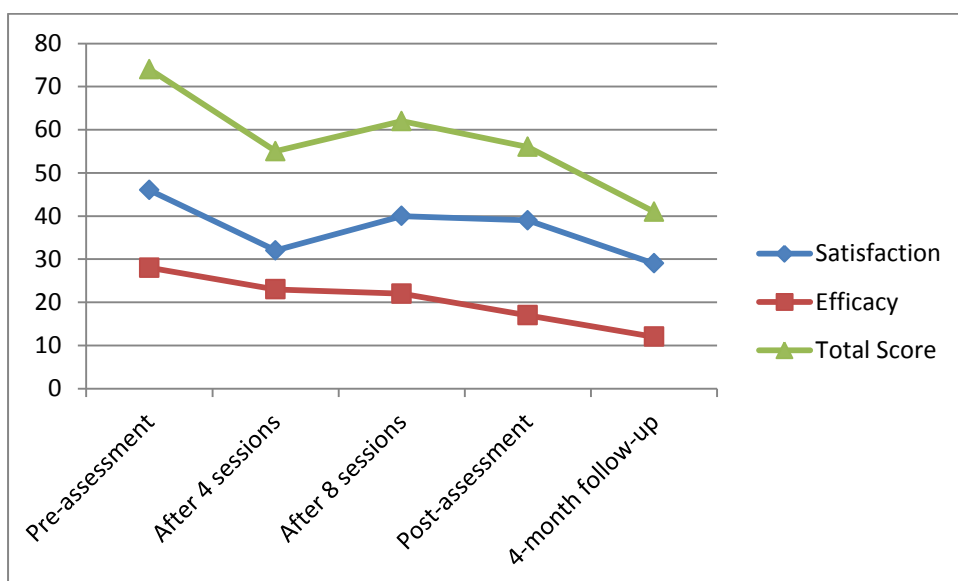
The Beck Depression Inventory II



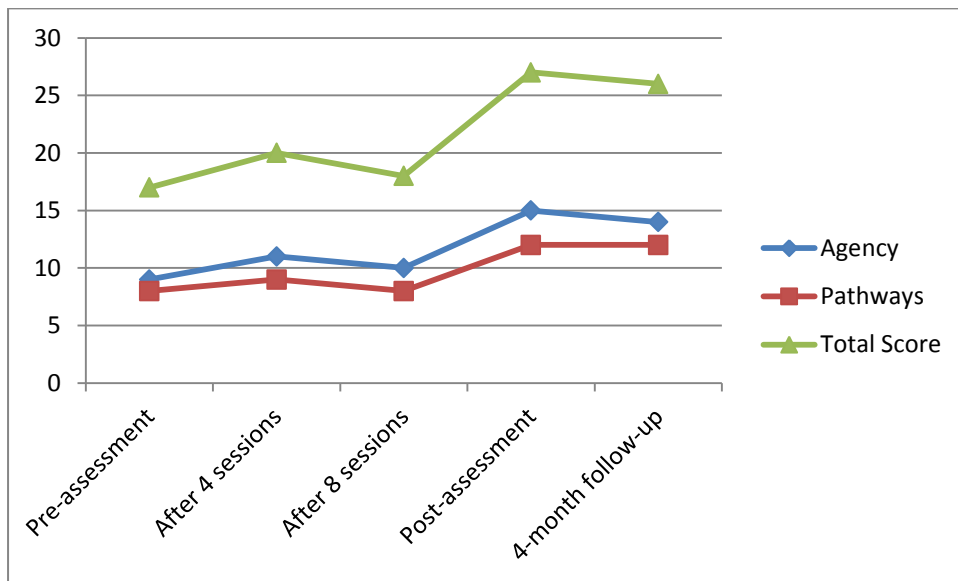
The Parental Locus of Control Scale



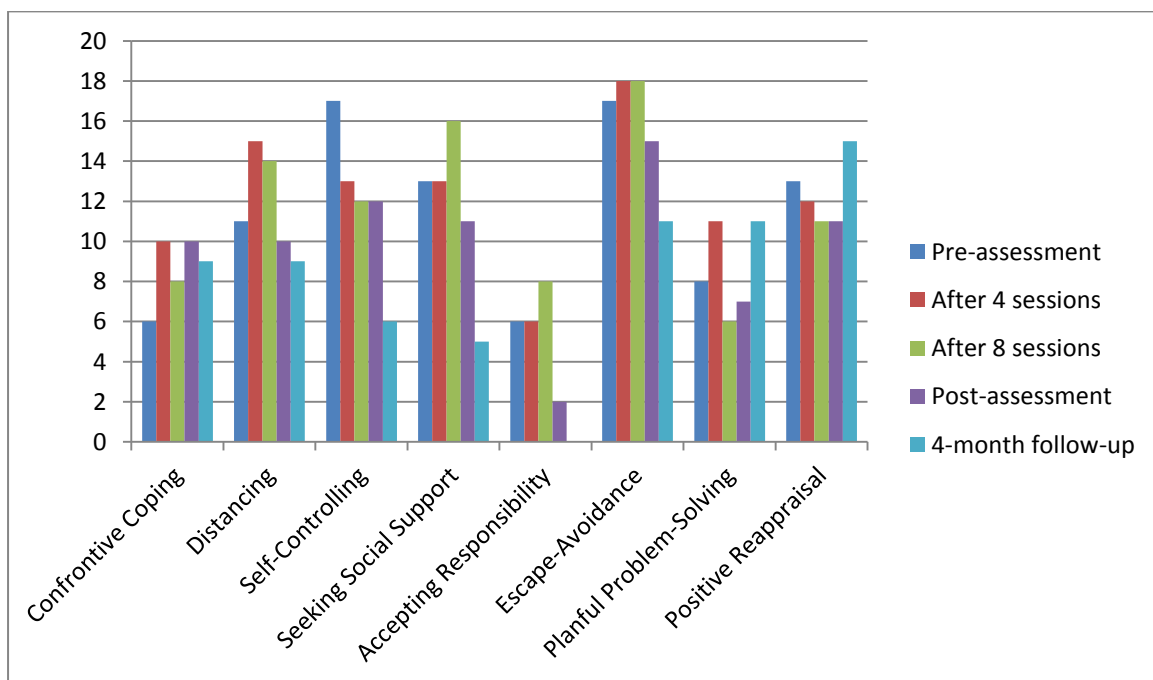
The Parenting Sense of Competence Scale



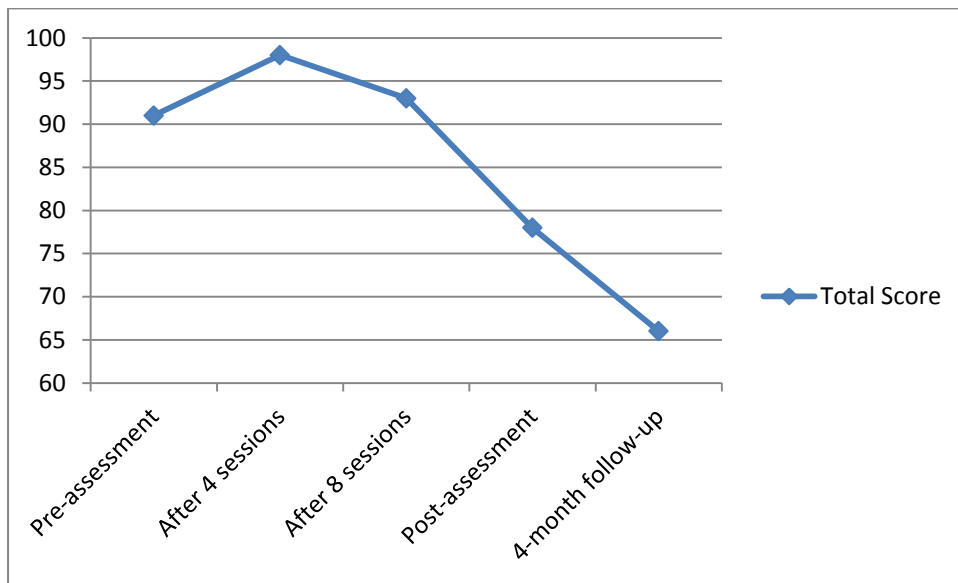
The Hope Scale



Ways of Coping Questionnaire: The Eight Ways of Coping



Ways of Coping Questionnaire: Total Score



3.2.7 Discussion

3.2.7.1 Attribution style of her children's behaviour and affective states of guilt, sadness and anger

a) Attributions associated with depression

Research has found an association between attribution errors and depression (Bentall & Kaney, 2005; Brewin, 1985; Brooks & Clarke, 2011; Gordon, Friedman, Miller, & Gaertner, 2005; Sturman, Mongrain, & Kohn, 2006; Wall & Hayes, 2000)

Persons who are depressed are more likely to interpret the causes of stressful and negative life events as the result of their own making (internality). Such events are also more often considered as fixed or stable through the course of time; and the consequences of such occurrences tend to be generalised as having a perceived impact on other parts of their daily existence (global attributions) (Brewin, 1985; Brooks & Clarke, 2011; Sturman et al., 2006).

As described in the narratives, at the onset of therapy Linda attributed all her psychological distress to Tony's behavioural difficulties. These global attributions went against available evidence that suggested different interpersonal, work-related and social-economic stressors.

I am not suggesting that Linda had no insight into the other stressors that were linked with her depression and parental stress. She was aware that her relationship with Kim was strained, and she readily described her marital conflict which had persisted over many years. Rather, my sense was that Linda minimised the impact of her other stressors against the caregiving challenges that she faced with Tony. The unpredictability of behavioural outbursts left her without much control over adverse caregiving events. In this manner, Linda's sense of helplessness was

reinforced and contributed to her depression. I believe that some of her helplessness proliferated to other areas in her life. On a general level, her helplessness constituted fixed and global attributions.

b) Internal attributions of being responsible for the development of epilepsy and its possible relationship with sadness and guilt

Linda's assertion that she was to blame for Tony's epilepsy suggests possible misattributions of internality. Despite the lack of evidence that she was to blame for her child's medical condition, Linda continued to discard the re-assurances of specialists that Tony's epilepsy was most likely congenital.

As described in the narratives, her beliefs were based on a number of adverse incidents in Tony's early childhood and infancy.

Significantly, most of these events did not result in syncope or required hospitalisation or even medical care. It should also be noted that the onset of Tony's epilepsy occurred years later.

At an almost superstitious level, Linda also believed that Tony's epilepsy was a form of punishment for her involvement in an extramarital affair.

Linda's misattribution of causing Tony's epilepsy could be seen as internal attributions that led to sadness, self-blame and feelings of guilt. While internal attributions are at times connected to an internal locus of control, this is often not the case (Weiner, 1985). Thus, even though depressed individuals tend to attribute the causes of negative events to themselves, it does not follow that they have *control* over those situations. The controllability of the situation becomes another level of attribution (Weiner, 1985).

On a deeper level, I believe that Linda blamed herself for leaving Tony in her husband's care. She had to go to work to earn a living, and had little choice but to leave her infant daughter on the farm. At the time her husband was already suffering from addiction. He was not formally employed and she was the only one in the family who earned a regular income. Hence, Linda had limited control over these events; she also had limited agency to rectify matters because of the marital conflict and the constant battle to survive financially and emotionally.

When examining Linda's belief system on this level, her guilt and self-blame about Tony's epilepsy become more explicable. Linda confirmed that she was constantly worried about her infant daughter when she was at work; she felt helpless and angry about her husband's drinking habits. More specifically, Linda worried that something *bad* might happen to Tony when she left her child at home with him. A number of years later, the onset of Tony's epilepsy represented a traumatic and painful experience. I believe that this activated similar beliefs regarding helplessness, uncontrollability and guilt.

c) Internal attributions of being responsible for the conflict with her youngest child and its possible relationship with sadness and guilt

I noted a similar attribution style of internality with regard to Linda's conflict with Kim. Her feelings, which included anger, sadness, guilt and frustration, were linked with beliefs that Kim acted out because Linda was a bad parent. Accordingly, Linda stated that she did not display enough affection towards her youngest child. Furthermore, she was often exhausted and irritable towards Kim because of her long working hours and Tony's caregiving responsibilities.

Whilst Linda blamed herself for the conflict with her youngest daughter, she simultaneously perceived her daughter's behaviour as disrespectful, rebellious and deliberate. During the course of therapy, Linda had often stated that Kim was deliberately oppositional and disrespectful. Attributions of responsibility or intentionality, that Kim was "difficult" and oppositional on purpose, left her with feelings of frustration and anger.

Attributions of responsibility are associated with anger (Armstrong & Dagnan, 2011; Weiner, 1985).

d) Attributions of responsibility and maternal feelings of anger towards Tony

Linda's anger towards Tony was embedded in similar beliefs. During the earlier parts of therapy, she repeatedly referred to Tony's problem behaviours as deliberate attention-seeking.

Attributions of responsibility and intentionality were usually accompanied by phrases such as "she knows exactly what she was doing". As I described earlier, Linda vacillated between beliefs that Tony's behaviour was caused by information-processing deficits and epilepsy; at other times she saw her child's conduct as almost purely intentional.

Parents of children who have ID and problem behaviours need to assume that their children have some control over their behaviour in order to enhance their receptivity to corrective parental input. However, if a child displays behavioural problems, parental views of controllability over such behaviours may also result in anger and blame (Woolfson & Grant, 2006; Woolfson et al., 2010).

I believe that psychoeducation assisted Linda to shift some of her attributions towards a more balanced view of Tony's behavioural difficulties. More specifically, Linda acquired a basic understanding of the impact of symptoms of psychosis and non-convulsive frontal seizures on Tony's erratic displays of aggression. On a more subtle level, our discussions about Tony's epilepsy and subsequent cognitive decline might also have re-sensitised Linda to Tony's own painful experiences of loss. As a tentative statement, I observed less anger in Linda with regard to her children toward the end of therapy.

Like everyone else, Tony had her "*off days*" when she was irritable and unhappy. Unlike most, she had severe medical complications and psychiatric problems with high levels of illness intrusiveness.

3.2.7.2 Aspects of personality and interpersonal conflict across different relationships

Linda's feelings of anger were not restricted to her relationship with her children. As described in the narratives, Linda's relationship with her husband had been acrimonious for many years. Linda was also upset and resentful about the lack of support she received from relatives. This related to the caregiving of Tony and her husband's alcohol addiction. She was angry about the manner in which her brothers treated her elderly parents. On numerous occasions, Linda also became angry when discussing aspects of her interaction with various health care professionals. She reported conflict with her supervisors at work. Linda also got angry and upset with me on more than one occasion.

Being cautious about labelling her after only ten sessions of psychotherapy, I tentatively linked some of her anger and interpersonal conflict to traits of borderline

personality. Her decision to stay in an acrimonious marriage was conceptualised as possibly representing a fear of abandonment. Uniformly positive or negative descriptions of health care professionals at times resembled the defence mechanism of splitting.

Aspects of parental personality have been linked with maternal depression among parents of children who have ID (Glidden et al., 2006, 2010; Glidden & Natcher, 2009). I therefore conceptualised some of these traits as relatively stable phenomena that might have had an enduring impact on Linda's mood, relationships and her interaction with Tony.

3.2.7.3 Coping with depression and parenting stress

I believe that Linda's hopelessness, external locus of control and helplessness were linked with secondary appraisals that she had inadequate coping resources to deal with many of the stressful life events that she experienced. The narratives describe distressing family events that unfolded over the course of decades. Examples include the onset of Tony's epilepsy, her subsequent cognitive decline, ongoing financial stressors and Linda's marital problems. Her sense of being disconnected from family members could be traced back to early childhood.

Stress proliferation occurs if stressful events have a ripple effect in other areas of a person's life, whereby it is implied that original stressors such as caregiving demands may cause stress in other domains of functioning (Benson & Karlof, 2009).

It is therefore possible that Tony's high medical, nursing and behavioural support needs had a negative impact on Linda's occupational functioning and family life. We had to schedule our sessions in the evening because of Linda's workload. She also had to put in leave to accompany Tony to monthly medical appointments and visits

to understaffed pharmacies with long queues and waiting times. It is conceivable that her caregiving responsibilities were linked with her reports of exhaustion.

The Ways of Coping Questionnaire was used to measure Linda's coping strategies against ongoing caregiving stressors. Her responses were measured at different times as presented in the graphs of the previous section.

At first glance, I was confounded by the results which suggested that Linda progressively used fewer coping strategies to manage Tony's behavioural difficulties. When compared with baseline scores, Linda took less responsibility and employed less self-control. She also sought less social support even though she started to go out with friends for coffee. Other scales such as Positive Reappraisal and Active Problem-Solving showed little variation, although she used confrontive coping more frequently.

Against this, the shortened version of the PSI-SF reported significant reductions in parental stress. These gains were sustained at follow-up assessment after four months. In fact, her locus of control became more internalised; and post-assessment and follow-up scores on the different measurements of parental efficacy and satisfaction recorded significant improvement.

The psychometric test results made more sense once I had completed the thematic analysis of this case study. I believe that Linda had gained some insight into the aetiological complexity of Tony's behavioural difficulties. She started to take less responsibility after she had realised that many of Tony's behavioural outbursts were not representative of intentional acting out. Of course, respite in itself afforded Linda with tangible means to temporarily reduce her caregiving responsibilities.

I also believe that her improved relationship with Kim added to her overall parental satisfaction.

It is possible that elevated scores in Confrontive Coping signified her assertive efforts to obtain psychiatric help for Tony through the district hospital services. As her guilt lessened, she also became more assertive towards Kim by holding her to account if household chores were not completed.

Whilst in therapy, Linda's efforts to get her husband placed in an Old Age Home possibly suggested enhanced assertiveness. Yet she remained hesitant to seek alternative accommodation for Tony or escalate the situation through the appropriate channels. Perhaps understandably, Linda was also reluctant to openly disagree with health care professions about medication changes and Tony's discharge from hospital.

I remained concerned about the high levels of coexisting anger that was not adequately resolved in psychotherapy. Linda also continued to use strategies to avoid or escape from stressful situations. In this regard, escape-avoidance has been correlated with maternal depression among mothers of children with developmental disability (Glidden et al., 2006; Paster et al., 2009; Woodman & Hauser-Cram, 2013).

3.3 The Third Case Study: Jeanette

3.3.1 Introduction

At the time of therapy, Jeanette was a sixty-four-year-old married mother of three children who were aged between twenty-three and forty years. Her second eldest child, Cindy, was diagnosed with mild ID and bipolar mood disorder. Cindy also presented with obsessional behaviours that were considered to be part of a differential diagnosis of obsessive-compulsive disorder.

Jeanette was employed in the kitchen of a school for children with special educational needs. Her husband had been retrenched almost a decade before psychotherapy took place. Jeanette was the only family member with a regular income and all her children still lived at home. Although she was worried about the escalating cost of living in difficult economic times, she told me that Cindy's relationship with her husband remained her main stressor.

When I probed Jeanette about her daughter and husband's conflict, she indicated that her husband had been using alcohol excessively for more than three decades. Most of their conflict occurred when he was intoxicated. She also described intermittent episodes of physical and verbal violence against herself and Cindy.

Jeanette presented with parental stress that appeared to be closely connected with Cindy's agitated behaviour during family conflict and domestic violence.

Cindy's clinical profile was characterised by discrete episodes of verbal and physical aggression that were often directed towards her mother. Cindy also displayed obsessional behaviour towards specific persons. At the time of therapy, Cindy was concerned over the well-being of an adolescent whom she had met at church. He was recently diagnosed with cancer. She started to phone him at different times of

the day and often late at night. His family became annoyed about the phone calls and requested that she stop phoning their child. Yet Cindy persisted and she even approached strangers in the community to ask for airtime to phone him. Jeanette found the management of Cindy's behaviour difficult. When she tried to restrict phone calls, Cindy often became verbally aggressive.

Jeanette's mood was euthymic despite the prevailing challenges at home.

Nonetheless, she presented with high levels of parenting stress and ranked her subjective distress about Cindy's behaviour at about 80 before the onset of therapy.

3.3.1.1 Use of psychometry in this case study

Jeanette was reasonably fluent in English and presented as an articulate and intelligent woman. With only six years of formal schooling, Jeanette struggled to complete our first psychometric assessment. She did not grasp many of the psychological concepts of different items; and I observed psychological discomfort and an increased sense of embarrassment and agitation. I therefore decided to discontinue psychometric testing after two tests had been completed. Symptom checks were used instead to measure different psychological states that included parental stress.

3.3.2 Case formulation

3.3.2.1 Predisposing factors

Jeanette described unhappy childhood memories. She hailed from the Western Cape's wine-producing countryside and grew up on a farm:

Jeanette: My pa het my ma baie *abuse*. Hy was lief vir haar, (maar) hy het vir haar baie abuse en hy het baie gedrink! (*My father often abused my mother. He loved her, (but) he abused her a lot and he drank a lot!*)

Similar to her father's relationship with her mother, her husband often became violent and aggressive when he was intoxicated.

I believe that Jeanette's early formative influences shaped many of her opinions about intimate partner violence (IPV) and marriage. She told me that husbands are capable of displaying love and abuse. Women should accordingly be subservient and accepting in an almost unconditional fashion despite the obliquity of their spouses:

Jeanette: Ek is maar onderdanig vir hom want die vroue moet maar hulle manne onderdanig wees al is die manne verkeerd ook en vir party vroue is dit swaar.

(Jeanette: I am subservient because women must be subservient to men even if the men are wrong, which is difficult for some women.)

Jeanette would often use religion to positively reappraise the meaning of adverse family events such as her conflict with her husband, Martin, and Cindy's behavioural difficulties.

3.3.2.2 Precipitating factors

Jeanette's parental stress was sustained by worrying thoughts and emotional distress about Cindy's behavioural difficulties, well-being and safety. The relationship between Cindy and her husband was especially distressing. Jeanette was constantly worried about the possibility of conflict, arguments and verbal or physical abuse against her daughter. She told me that her husband was prone to become irritated and frustrated by Cindy's obsessional behaviour, especially when he was drinking.

Jeanette was also concerned about Cindy's supervision during the day. She had to leave her child alone with her husband. There were also increasing reports of her daughter's wandering behaviour in an unsafe neighbourhood that had its fair share of violent crime. Some of Jeanette's friends had recently seen Cindy approaching strangers for airtime at shops and street corners. As Jeanette continued to discuss her concerns in an almost stoic manner, I became increasingly worried about their circumstances and her daughter's vulnerability in the community.

3.3.2.3 Maintaining factors

Close to four decades of formal employment failed to eradicate financial insecurity. Jeanette was ambivalent about her retirement. Although she was looking forward to spending more time with Cindy, she continued to worry about the financial implications of her departure from work.

However, at the time of therapy, Jeanette worked shifts and did most of the family's domestic work. With so much on her plate, Jeanette often opted to avoid conflict by using escape behaviour and avoidance: she went about her business at home, often in the midst of arguments between Cindy and her husband.

Jeanette experienced dissonance and there was evidence of more assertive behaviour towards Martin. At times she made concrete efforts to de-escalate and resolve family conflict. Her efforts to manage the situation at home tended to depend on her fluctuating levels of energy and general capacity to deal with distress. Her descriptions depicted an emotional build-up and ongoing rumination in the face of adversity. She tolerated her husband's behaviour until an arbitrary point before confronting him.

Jeanette's ongoing worry about Cindy's wandering behaviour could be traced back to an event that occurred eight years ago. She became visibly upset and emotional when she recalled that her daughter was raped by unknown men in the community whilst she was wandering around their neighbourhood.

Cindy also overdosed on medication in 2004. She was subsequently hospitalised in a psychiatric unit and treated for depression.

With limited manoeuvrability in terms of social and human capital, Cindy and Jeanette remained vulnerable to abuse; and the risk of other adverse incidents in Cindy's life continued to be high. Yet social services were familiar with their circumstances. Against this background, it is commendable that Jeanette had received counselling from a social worker to assist her with IPV and trauma.

However, to me, this was clearly not enough. Jeanette's husband needed rehabilitative intervention; and Cindy's vulnerability raised questions about her family living arrangements, parental supervision and the possibility of placement in a community-based residential home.

3.3.3 Narratives of psychotherapy sessions

Session one

The first session was used to explore the presenting problems which included high levels of parental stress. We also discussed other significant psychological stressors that might have contributed indirectly to her caregiving challenges.

There were two themes that reverberated through all the sessions: First, Jeanette constantly ruminated about adverse caregiving experiences that occurred in the past and the possibility of a recurrence of similar events in future. For example, in this

session, Jeanette was worried that her child was again contemplating suicide. Although a recent psychiatric evaluation did not identify signs of suicidal ideation, Jeanette's fear of another suicidal attempt was not allayed:

Afrikaans:

Jeanette (huil): Toe dink ek aan die pille. (Onderbreking)

OC: Hierso is 'n paar tissues!

Jeanette: Ek het gister . . . toe dink ek aan die pille wat ek nie weg gesit het nie.

OC: Ja. Waaroor *worry* Jeanette wat die pille aanbetref?

Jeanette: Ek dink aan die pille want . . . gister by die hek toe dink ek: Ek het mos nie die pille weggesteek nie en sy het 'n manier . . . sy soek . . . Sy krap (rond)!

OC: Mm. En Jeanette was bekommerd dat sy van daai pille gaan drink, te veel, weer?

Jeanette: Ekke . . . Ek kry daai gevoel.

English translation:

Jeanette (crying): Then I thought about the pills. (Pause)

OC: Here are some tissues!

Jeanette: Yesterday when I . . . then I thought about the pills that I did not put away.

OC: Ja. Why is Jeanette worried about the pills?

Jeanette: I think about the pills, because . . . yesterday at the gate I thought:
But I did not hide the pills and she has a way . . . she seeks . . . She scratches
(around)!

Jeanette's references to the substance abuse of her husband and eldest son were largely obscured by descriptions of her caregiving responsibilities towards Cindy. At times Jeanette slipped these topics into our conversation, only to immediately reassure me that Martin was otherwise a good husband.

She changed the topic when I asked her *directly* about Martin's substance abuse and told me that he kept the house in mint condition. Being particularly affronted about her husband's verbal abuse against her daughter, at this early stage of therapy I took notice of her guardedness and conceptually attributed it to possible embarrassment and shame. Despite her reluctance to openly describe these matters Jeanette recognised the impact it has on Cindy:

Afrikaans:

OC: Is Cindy vir Jeanette die grootste bekommernis? Ne? Ja. Ok. So ons gaan bietjie daaroor ook praat, ok, baie goed. Maar ek hoor wat Jeanette sê . . . ek maak 'n nota daarvan . . .

Jeanette [kruispraat]: Mm, ja.

OC: Ons gaan definitief weer terugkom hiernatoe.

Jeanette: [kruispraat] Mm, ja.

OC: Ok . . . (stilte)

Jeanette: Want as ek aankom na die huis toe dan dink in my gedagte . . . ek hoop nie ek gaan nou weer 'n negatiewe iets hoor nie.

OC: Van mense wat praat oor Cindy?

Jeanette: Nee, veral van haar pa, of van haar.

OC: [kruispraat] Ja!

Jeanette: Ek hoop in my hart dinge gaan reg wees.

OC: Ja-ja. Sê vir my . . . hm-mm . . . as dit nou (kom) by Martin se manier van Cindy hanteer . . . vertel vir my meer . . . ?

Jeanette: Hy het nogal rustig geraak na die Polisie, maar soms tyd soos gister [sic] . . .

OC [kruispraat]: Mm.

Jeanette: Gister wat hy nou sien sy hou aan en al die . . . toe sê (hy): *“Die kind is mal; die kind makeer nog 'n klomp pille.”*

OC: Ja?

Jeanette: *“Hulle moet die pille meer maak.”*

OC: Ja-ja.

Jeanette: Toe sê sy-sy wens daai man gaan dood.

English translation

OC: Is Cindy Jeanette's greatest concern? *Ne?* Yes. Okay. So we will talk a bit more about it, okay, very well. But I hear what Jeanette is saying. . . . I am making notes . . .

Jeanette [cross talk]: Mm, ja.

OC: We will definitely get back to this.

Jeanette: [cross talk] Mm, ja.

OC: Ok . . . (silence)

Jeanette: Because when I approach home I think in my mind: I hope I will not again hear something negative.

OC: About people talking about Cindy?

Jeanette: No, especially about her father, or about her.

OC: [cross talk] Ja!

Jeanette: I trust in my heart that things will be all right.

OC: Yes. Yes. Tell me . . . mm-hm . . . when it (comes) to the manner in which Martin is managing Cindy . . . tell me more . . .? Ja!

Jeanette: He has become rather peaceful since the police, but some time like yesterday [sic] . . .

OC [cross talk]: Mm.

Jeanette: Yesterday, what he now saw (is that) she persisted and all the . . . then (he) said: *"The child is crazy; the child needs a bunch of pills."*

OC: Ja?

Jeanette: *"They must increase her tablets."*

OC: Ja-ja.

Jeanette: Then – then she said that she wished that man will die.

Based on our discussion, we identified the following therapeutic goals:

- To significantly reduce parenting stress and worry.
- To bolster coping with regard to the conflict with her husband and the conflict between Cindy and her husband.
- To look at ways of managing Cindy's behaviour difficulties more effectively.

Session two

Symptom checks suggested some improvement (parenting stress down to 50 from 80; her psychological distress from marital conflict decreased from 70 to 50).

Jeanette bridged the session by describing an incident that occurred after she had arrived home earlier in the week. She went to the fridge and thought that the twenty-six-year-old appliance had finally broke down. Martin blamed her for "breaking everything" (*"breek alles"*) despite the fact that she was not at home when the fridge had stopped working.

Jeanette told me that she was constantly apprehensive about the possibility of arriving home amid conflict and arguments between Martin and Cindy, especially when he was intoxicated.

With more candour than was noted in the previous session, Jeanette voiced her anger towards Martin and told me she will never again marry a husband “who drinks” (“*wat drink*”). Yet as shown in the extract below, she avoided further conflict with Martin:

Afrikaans:

OC: En toe hy vir Jeanette nou konfronteer en hy skel (jou), waaraan het Jeanette gedink?

Jeanette: (kort onderbreking) Ek moet nou weer dink. Ek het nou geluister na die woorde en ek voel ook nie om meer te luister nie. Ek het net gedink: Laat dit maar net verby gaan.

English translation:

OC: And when he confronted Jeanette and he scolded (you), what was Jeanette thinking about?

Jeanette (short pause): I will have to think (about it) again. I just listened to the words and I felt I do not want to listen anymore. I just thought: let it just go by!

However, Jeanette also provided a glimpse of the possible consequences if she openly displayed her dissatisfaction during conflict:

Afrikaans:

Jeanette: Ek gaan . . . ek het hom eendag ‘n hou gegee. Toe val ek; toe waai ek soos ‘n stuk lap oor die *tiles*.

OC: Ai!

Jeanette: Maar nee, daar het ek besef: Nee, los maar, 'n man is sterk.

English translation:

Jeanette: I shall . . . One day I poked him. Then I fell; then I flew like a piece of cloth over the tiles.

OC: Ai!

Jeanette: But no, then I realised: no, leave it, a man is strong.

Session three

Jeanette's symptom checks were slightly elevated from the previous session at 60 for parental stress and 70 for her psychological distress about the conflict with Martin.

Jeanette became very emotional and cried forlornly whilst describing an event that saw Martin beating their puppy after the dog had chewed and disconnected a water pipe in their backyard. She told me that she waited for her husband to return to bed before making sure that the puppy was still alive and without broken bones. She stated that the puppy's howling stayed with her for the rest of the day.

Jeanette sought support from her friends at work and told them what had happened. She also visited a social worker to discuss her husband's drinking habits. Although the social worker was unable to deliver on her promise of a home visit, Jeanette told me that she felt better for raising the issue with this person.

She described Cindy's agitation after Martin had started to beat the puppy. She had to leave her daughter at home to go to work, knowing well that her husband was irritable and not yet sober from a night's heavy drinking. In this context, I believe that

a non-confrontational approach reduced the possibility of conflict between Cindy and her father after Jeanette had left for work. I also conceptualised her visit to the social worker as a way of seeking social support.

Jeanette struggled with the basic tenets of CBT. She found it difficult to make accurate Belief-Emotion links. We therefore focused more on the behavioural aspects of her coping.

Session four

While her subjective rating scales for parental stress remained unchanged at 60, her rating marital conflict and distress went down from 70 to 40.

Jeanette told me that she had accepted her husband's alcoholism. In another development, Jeanette stated that she deliberately avoided any discussion of important matters with Martin in the evening. She now approached him in the morning when he was not intoxicated.

We decided to allocate more time to talk about the management of Cindy's behaviour. Jeanette told me that Cindy was becoming progressively more reserved and withdrawn. Her daughter lost her appetite and slept less. Jeanette believed her daughter's withdrawal was either the result of her preoccupation with her friend or she was becoming suicidal again.

She reported that Cindy was increasingly obsessional and tried to contact her friend at various times of the day. She took Jeanette's bank card out of her purse and withdrew fifty rand from an automatic teller machine. She used all the money to buy airtime and then tried repeatedly to phone her friend.

On top of these concerns, Jeanette was also worried about Cindy's physical health following a bout of gastroenteritis. However, she failed to connect Cindy's withdrawal with possible physical discomfort and post-viral malaise. Jeanette spontaneously burst out laughing after realising that Cindy's change in behaviour might also be accounted for by acute medical problems.

As described earlier, our intervention was more focused on practical and behavioural steps to lower Jeanette's parenting stress and relationship problems. Hence, while I was more directive than I would like to be, a suggestion to keep Cindy's medication in her handbag further enhanced her sense of control. Cindy would not be able to overdose on medication if she did not have unsupervised access to it.

We also agreed that Jeanette would take Cindy's phone with her to work. She agreed to monitor Cindy's use of her mobile phone in the evening when her daughter had access to it again.

Jeanette felt ambivalent about our decision, and I picked up that it possibly made her feel guilty. We decided to explore the issue in the next session. The storage of medication in her handbag and the confiscation of her child's cell phone during the day constituted forms of stimulus control. I thought that such measures were warranted by the risk that Cindy's current behaviour posed to her safety.

Drastic measures such as restricting Cindy's access to her mobile phone may seem rather punitive and even as a violation of Cindy's basic human rights. However, I believe that the context here should be explicitly acknowledged: Cindy's wandering behaviour was usually restricted to their neighbourhood. However, people in Cindy's neighbourhood knew her and the family had community connections through their church. This implied that there were individuals who kept an eye on Cindy when she

wandered around during the day. Of late, she had approached strangers to beg for money in order to phone her acquaintance. She was seen by Jeanette's friends in parts of town known for prostitution, gangsterism, armed assault and illicit drug-related activities.

Session five

Subjective measures of parental stress came down from 70 to 40; and her distress about marital conflict likewise continued its downward trajectory from 40 to 30.

I asked Jeanette why she was feeling better. She answered that she was accepting her husband's drinking and all the negativity regarding it. This answer did not feel entirely congruent and authentic.

Analysis suggested that she started to use different coping strategies and became more proactive in her efforts to *manage* Martin's drinking and abuse. She mentioned again that she now reserved time in the morning to talk to him about household matters. Jeanette also provided feedback that she followed-through on the two decisions we had made in the previous session with reference to the cell phone and Cindy's medication.

It is possible that the employment of these coping strategies had contributed to an enhanced sense of self-efficacy. It also moved her towards a stronger internal locus of control.

I also believe that Jeanette became more *consistent* in her use of different coping strategies. For example, when Cindy was agitated after her requests to phone her friend had been refused, unlike previous incidents, Jeanette did not capitulate by giving her the phone. Jeanette's persistence possibly laid the groundwork for

response prevention and habituation to counter her daughter's compulsive behaviour.

When Martin lashed out at Cindy after she had brought him a newspaper with some of the sections missing, Jeanette pushed Cindy into her room and locked the door. She discussed the incident with him the following morning.

Session six

Jeanette's symptom checks for parental stress and her distress about marital conflict were both ranked at 20.

We shifted our focus from parental stress and family conflict to the management of Cindy's behaviour. This part of therapy comprised teaching and parental training.

Jeanette described Cindy's behavioural outbursts and we systematically explored the context in which such events occurred. It emerged that Cindy's aggressive behaviour was often instigated by family conflict and the arguments she had with her father. Against this background, Cindy displayed verbal and physical aggression that was directed towards other family members. Following descriptions of such events I realised that Jeanette's efforts to calm her daughter down were often rendered ineffective by Cindy's high levels of arousal. At other times Jeanette avoided conflict by withdrawing from the situation.

In addition to family conflict, Cindy also tended to react aggressively when Jeanette refused to buy her airtime to phone her friend. Jeanette told me she was left with no choice but to meet her child's demands even though she knew that this would cause "*trouble*" ("*moeilijkheid*") with the boy's family.

We explored the dynamics behind the implicit negative reinforcement of demanding behaviour and compulsive phoning. By allowing her child to phone, Jeanette was effectively increasing what behavioural therapists would refer to as undesirable behaviours. If we were to fortify and enhance Jeanette's management of Cindy's behaviour, the context of Jeanette's negative reinforcement, and the positive intention behind it, had to be understood.

Jeanette stated that Martin was often annoyed by Cindy's demands. I prompted her about her fears when Martin reacted to Cindy's demands. Perhaps unsurprisingly, Jeanette was fearful that Cindy's demands for airtime and Martin's corresponding annoyance would rapidly escalate into family violence. In this context, the provision of airtime appeared to be, for lack of a better and more sophisticated description from my side, the lesser of two evils.

In addition to her apprehension and presaging feelings about family violence, Jeanette recalled a recent incident that saw Cindy leaving the house late at night after Jeanette had refused to buy her airtime.

We were able to discuss the risks that Cindy's wandering posed to her safety. It became apparent that Jeanette at times felt guilty about restricting her daughter's movements despite the safety risks that Cindy's wandering behaviour posed. More specifically, Cindy tended to act out when her mother restricted her movements. Besides feeling guilty, Jeanette told me that she felt upset when her daughter started crying. We explored her feelings and perceptions regarding the management of Cindy's wandering behaviour, and Jeanette reported that she felt less guilty following our conversation:

The functionality and positive intention behind Jeanette's negative reinforcement of Cindy's demanding behaviour and compulsive phoning were better understood once her behaviour was seen as an attempt to mitigate the risk of family violence.

In fact, to me the session highlighted the limitations of narrow behavioural conceptualisations that focus unilaterally on the eradication of negative reinforcement through the use of differential reinforcement schedules.

The low arousal approach considers problem behaviours among people who have intellectual disability to be the result of socially-constructed behaviours that emerge from the dynamic interaction between parent and child. Whereas behavioural therapy targets the behaviour of the child, the low arousal approach focuses on the arousal levels of parent and child during times of crises (Matson et al., 2012; McDonnell, 2010; Spiegler & Guevremont, 2003).

From Jeanette's descriptions it became evident that she was propelled into a state of heightened agitation when her daughter started to plead for airtime. Fearing family violence, Jeanette tended to become agitated when Martin was around. Thus, she would generally lock the door and ignore her daughter's appeals as a first step. However, she would summarily give in to Cindy's requests the moment her husband became involved. By postponing discussion about the management of Cindy's behaviour with Martin to the following morning when he was sober, Jeanette managed to increase her control over situations such as the one that was described in this session.

Session seven

Jeanette's parental stress came down to 20 from a baseline assessment of 80. Her psychological distress about the conflict at home decreased from 70 to 20.

Thematically, the session was less rich than the previous two sessions. Jeanette mentioned that she felt less guilty about her daughter's problems and the adverse incidents that occurred in the past.

Jeanette also voiced her concern about the manner in which Cindy was treated by her extended family and people in her community. We put the issue of stigmatisation on the agenda. Jeanette became tearful when recalling an incident that occurred after her mother-in-law had passed away. Cindy refused to greet other family members when the funeral took place. She told me that her family did not understand how difficult it was to raise a child with disability.

3.3.4 Interview after psychotherapy had been terminated

Jeanette highlighted the practical gains that she made in therapy and emphasised two outcomes: First, she told me that she had a better understanding of Cindy's behavioural difficulties. She became more active by limiting Cindy's access to her mobile phone; and she now often ignored some of Cindy's verbal aggression when such incidents occurred.

Furthermore, Jeanette again stated that she changed her strategies regarding the management of conflict between Cindy and her husband. She again described the benefits of discussing family issues with Martin in the morning. She was also more assertive towards Cindy.

3.3.5 Themes that emerged from thematic analysis

Theme	Excerpt
Growing-up in a dysfunctional family: Formative influences and observations of Intimate Partner Violence and substance abuse as typical family experiences	<p><i>Jeanette: My pa het my ma baie abuse. Hy was lief vir haar, (maar) hy het vir haar baie abuse en hy het baie gedrink.</i></p> <p>Jeanette: My father often abused my mother. He loved her, (but) he abused her a lot and he drank a lot.</p>
Parental stress about husband's harsh parental practices, neglect and conflict with Cindy	<p><i>Jeanette: Ek het dit baie geniet, maar toe ek nagskof gewerk het was ek baie gespanne, want my man het tot twaalf uur somtyds by sy vriende domino's gespeel. Dan moet ek bel om te se . . . dan is Cindy toegesluit in die kamer.</i></p> <p>Jeanette: I enjoyed it a lot, but when I worked night shift I was very tense, because my husband sometimes played dominos until twelve o'clock. Then when I phoned to say . . . then Cindy was locked in her room.</p> <p><i>Jeanette: Weet u, ek was so kalm gewees daai oomblik: Ek het vir Cindy gevat en in die badkamer gaan druk toe sê ek: "Jy moet maar vir my slaan; jy gaan nie vir Cindy slaan nie!"</i></p> <p>OC: <i>Ja, toe wat doen hy toe?</i></p> <p><i>Jeanette: Hy het vir Cindy woorde daar gesê [sic] . . .</i></p> <p>Jeanette: You know, I was so calm in that moment: I took Cindy and pushed her into the bathroom and then I said: "You must hit me; you will not hit Cindy!"</p> <p>OC: Ja, and what did he do then?</p> <p>Jeanette: He said words to Cindy there [sic] . . .</p> <p><i>OC: Nou, waarvoor was Jeanette bang toe Jeanette sien Martin staan daar en skel vir Cindy? Wat was Jeanette bang voor?</i></p>

	<p>Jeanette: Die klap gaan kom.</p> <p>OC: Now, what was Jeanette afraid of when Jeanette saw Martin standing there and scolding Cindy? What was Jeanette afraid off?</p> <p>Jeanette: The blow will come.</p> <hr/> <p><i>Jeanette: En vir Martin het ek al 'n afspraak gemaak; ek het al probeer om 'n afspraak te maak hier by die Polisie stasie om oor die familie dinges.</i></p> <hr/> <p>Jeanette: And for Martin I have tried to make an appointment; I have tried to make an appointment with the police before about the family gimmicks.</p>
<p>Rumination about distressing parental events of the past and worry about the possibility of similar events in future</p>	<p><i>Jeanette: Ek het gister . . . toe dink ek aan die pille wat ek nie weg gesit het nie.</i></p> <p>OC: Ja. Waaroor worry Jeanette wat die pille aanbetref?</p> <p><i>Jeanette: Ek dink aan die pille want . . . gister by die hek toe dink ek: Ek het mos nie die pille weggesteek nie en sy het 'n manier: sy soek . . . sy krap (rond)!</i></p> <p>OC: En Jeanette was bekommerd dat sy van daai pille gaan drink? Te veel, weer?</p> <p><i>Jeanette: Ekke . . . ek kry daai gevoel.</i></p> <hr/> <p>Jeanette: Yesterday when I . . . then I thought about the pills that I did not put away.</p> <p>OC: Ja. Why is Jeanette worried about the pills?</p> <p>Jeanette: I think about the pills, because . . . yesterday at the gate I thought: But I did not hide the pills and she has a way . . . she seeks . . . She scratches (around)!</p> <hr/> <p><i>Jeanette: Maar ek het ook besef, ek hoef</i></p>

	<p><i>nie om skuldig te voel nie.</i></p> <p><i>OC: Ja-ja.</i></p> <p><i>Jeanette: Dit is nie my skuld nie,</i></p> <p><i>OC: Ja-ja.</i></p> <p><i>Jeanette: In die verlede het sy mos al deur verkragtings gegaan, maar . . .</i></p> <p><i>OC: Slegte goed, ja.</i></p> <p><i>Jeanette: Sy het darem gelukkig nie die AIDS opgedoen nie . . .</i></p> <hr/> <p><i>Jeanette: But I also realised, I don't need to feel guilty.</i></p> <p><i>OC: Ja-Ja.</i></p> <p><i>Jeanette: It was not my fault.</i></p> <p><i>OC: Ja-ja.</i></p> <p><i>Jeanette: In the past she went through rapes [sic], but . . .</i></p> <p><i>OC: Bad things, ja.</i></p> <p><i>Jeanette: She fortunately did not contract AIDS . . .</i></p>
<p>Parental stress because of Cindy's wandering behaviour: Worrying about her daughter's safety in an unsafe neighbourhood</p>	<p><i>Jeanette: Ja, en dan stap sy net 'n koers in soos sy een aand gestap het toe-toe stap ek en iemand agter haar aan.</i></p> <p><i>OC: Ok.</i></p> <p><i>Jeanette: En ek-ek voel nie dat sy so in die donkerte moet stap nie want enige ding kan met haar gebeur.</i></p> <p><i>OC: Mm, ok. So die gedagte wat Jeanette laat magteloos voel is Cindy gaan weer skarrel?</i></p> <p><i>Jeanette: Mm!</i></p> <hr/> <p><i>Jeanette: Ja, and then she will just walk</i></p>

	<p>in a direction like the one evening when-when someone and I walked behind her.</p> <p>OC: Ok.</p> <p>Jeanette: And I-I felt that she should not walk like that in the dark, because anything can happen with her.</p> <p>OC: Mm, ok. So the believe that makes Jeanette feels powerless is that Cindy is about to scurry again?</p> <p>Jeanette: Mm!</p>
Maternal resilience: Recognising the need to be flexible, optimistic and face caregiving challenges head-on.	<p><i>Jeanette: As jy met sulke kinders werk of jy het so kind, dan moet jy eintlik elke dag verwag daar is 'n nuwe ding. Daar is dag [sic] en daar is iets, daar gaan iets gebeur. Of iets mooi!</i></p> <p>—</p> <p>Jeanette: If you work with children such as these or you have such a child, then you should expect something new every day. There is day [sic] and there is something, there is something that will happen. Or something beautiful!</p>
Problem-solving Cindy's obsessionalities and aggressive acting-out: Saying "no" with assertive parenting	<p><i>Jeanette: Dan kom sy daar aan dan vra ek: "Cindy, wie se selfoon is die?". Dan sê sy dit is Antie ** [persoon se naam] in ** [plek se naam]. Dan sê sy: "Mammie, Mammie moet nou praat!" Dan sê ek: "Cindy, loop! Ek weier die bel storie!"</i></p> <p>—</p> <p>Jeanette: Then she arrived and then I asked: "Cindy, whose phone is this?" Then she said it is Auntie ** [person's name] in ** [place's name]. Then she said: "Mommy, Mommy must talk now!" Then I said: "Cindy, walk away! (pragmatically translates as go away!) I refuse the story about phoning!"</p> <p>—</p> <p><i>Jeanette: Maar ek gee nie sommer haar sin ook nie. Gister toe sê ek vir haar: "Cindy, gaan saam met my!" Toe sê sy vir my: "Gee asseblief vir my 'n twaalfrand (vir) airtime" toe sê ek: "Ek gaan dit nie doen nie! Ek is jammer!"</i></p> <p>—</p> <p>Jeanette: But I don't just give her her</p>

	<p>own way. Yesterday I said to her: "Cindy, go with me." Then she said to me: "Please give me twelve rand (for) airtime." Then I said: "I can't do it! I am sorry!"</p> <p>— Jeanette: <i>Ek het geleer daar . . . ek het nie nodig om skuldig te voel as sy tantrums gooi nie.</i></p> <p>OC: <i>Nee.</i></p> <p>Jeanette: <i>Ek het nie nodig nie.</i></p> <p>OC: <i>Nee.</i></p> <p>Jeanette: <i>Want dit is vir haar eie veiligheid. (Jeanette hoes) Ek moet eintlik goed voel!</i></p> <p>OC: <i>Ja!</i></p> <p>Jeanette: <i>Om vir haar nee te sê . . . My nee moet nee bly.</i></p> <p>— Jeanette: I learnt that . . . I do not need to feel guilty if she throws tantrums.</p> <p>OC: <i>No.</i></p> <p>Jeanette: I do not need it.</p> <p>OC: <i>No.</i></p> <p>Jeanette: Because it is for her own safety. (Jeanette coughs) I should feel good!</p> <p>OC: <i>Ja!</i></p> <p>Jeanette: To say no to her . . . My no should stay no.</p>
Intimate Partner Violence (example)	<p>Jeanette: <i>Ek gaan . . . ek het hom eendag 'n hou gegee. Toe val ek; toe wai ek soos 'n stuk lap oor die tiles.</i></p> <p>OC: <i>Ai!</i></p> <p>Jeanette: <i>Maar nee, daar het ek besef: nee, los maar, 'n man is sterk.</i></p>

	<p>Jeanette: I shall . . . One day I poked him. Then I fell; then I flew like a piece of cloth over the tiles.</p> <p>OC: Ai!</p> <p>Jeanette: But no, then I realised: no, leave it, a man is strong.</p>
<p>The use of different coping strategies to deal with distressing family situations</p>	<p><i>Escape-avoidance/Distancing</i></p> <p>OC: <i>En-en toe hy vir Jeanette nou konfronteer en hy skel, waaraan het Jeanette gedink?</i></p> <p>Jeanette: <i>(Onderbreking) Ek moet nou weer dink. Ek het nou geluister na die woorde en ek voel ook nie om meer te luister nie. Ek het net gedink: Laat dit maar net verby gaan.</i></p> <p>OC: And-and when he confronted Jeanette and he started scolding (you), what was Jeanette thinking?</p> <p>Jeanette: (Pause) I have to now think again. I had listened to the words and I felt to not listen any more. I just thought: let it just pass!</p> <p><i>The use of religion to positively reappraise distressing family situations over which she has limited agency</i></p> <p>Jeanette: <i>Ek is kalm, ja. Ek is kalm, ek aanvaar. Ek aanvaar wat ek nie kan verander nie, want net die Here kan verander [sic].</i></p> <p>Jeanette: I am calm, ja. I am calm, I accept. I accept what I can't change, because only God can change [sic].</p> <p><i>Confrontive coping</i> <i>*see above for Afrikaans text</i> Jeanette: You know, I was so calm in that moment: I took Cindy and pushed her into the bathroom and then I said: "You must hit me; you will not hit Cindy!"</p>

3.3.6 Discussion

Jeanette impressed as a resilient woman with the wherewithal to forge ahead and cope with distressing life events. Resilience implies that a person has the capacity to maintain their core roles and responsibilities notwithstanding adversity (L. McCubbin, 2001).

Against this background, Jeanette held employment at the same school for over thirty years despite Martin's progressive battle against addiction and the intimate partner violence that continued unabatedly. Cindy's additional support needs and problem behaviour also added to Jeanette's everyday responsibilities.

Despite Jeanette's resilience and ability to engage in persistent life challenges, it should be added that the process of coping does not automatically translate into successful outcomes (Folkman, 1984; Folkman & Lazarus, 1988; Kelso et al., 2005; Lazarus, 1999).

Before therapy commenced, Jeanette used different coping strategies that proved successful in reducing psychological distress, especially in the short run. As described in the narratives, she used religion to find meaning in her experiences of adversity.

At times she tended to mentally disengage; and at other times she sought social support and used confrontive coping as well as planful-problem solving with varying degrees of success. For example, Jeanette dealt with the incident when Martin lashed out at the dog by conducting some form of inspection to ensure the puppy had no broken bones (accepting responsibility and problem-solving). She contained Cindy and went to the social worker to request professional support for her

husband's drinking and his abusive behaviour (accessing formal support; problem-solving; confrontive coping).

While strategies such as these ensured that she was able to maintain her functions as mother and breadwinner, at the onset of therapy, Jeanette's existing coping strategies of managing conflict and Cindy's behaviours were most likely less successful. Mental disengagement and intermittent confrontation did not adequately reduce her parental stress. In addition, her efforts to mitigate family conflict by giving in to Cindy's demands effectively reinforced her daughter's compulsive phoning and demanding behaviour. It was in the best interest of mother and child to discontinue these negative reinforcement patterns and develop more effective strategies to manage Cindy's behaviour.

In this case, the opportunity to work directly with a parent in a psychotherapy context sensitised me to the positive intentions behind the negative reinforcement of Cindy's behaviour. Thematically, Jeanette's case study elicited the potential usefulness of psychotherapy to explore key issues regarding parental stress and the child's behavioural problems:

It is possible that some of Jeanette's intentions might have been missed had we paid less attention to the family context in which Cindy's behavioural problems occurred. Jeanette's primary objective was to mitigate the risk that some of Cindy's obsessionalities and demanding behaviours may eventuate in family violence. Essentially, the de-escalation of conflict took precedence over the management of Cindy's problem behaviours.

Jeanette's use of mental disengagement and avoidant behaviour against IPV invites further exploration. It is possible that her prolonged exposure to IPV had most likely

contributed to feelings of disempowerment and beliefs of vulnerability, inadequacy and helplessness to deal with family conflict and her husband's abuse.

In fact, Jeanette's tended to provide positive depictions of Martin's character and the emotional support that she received from him immediately after she had mentioned episodes of abuse and battering.

The dissonance between expectations of protection, security and trust against continued and repeated episodes of abuse is documented in the literature (Bauman, Haaga, & Dutton, 2008). In such instances, beliefs are often distorted in an attempt to reconcile the person's expectations of safety and trust against her experiences of abuse within the context of an intimate relationship (Bauman et al., 2008)

Women who experience IPV often employ emotion-focused coping strategies to deal with a sense of vulnerability and distressing emotions such as shame, embarrassment, anger and fear. Mental disengagement or escape behaviour is one of the most frequently-employed emotion-focused strategies (Calvete, Corall, & Estévez, 2007; Iverson et al., 2013; Kanagaratnam et al., 2012).

It was only *after* the personal context of abuse and battering had been explored that Jeanette started to renegotiate and change some of her ways of coping with Cindy's behaviour. Her new insight into the negative reinforcement of Cindy's behaviour led Jeanette to extinct some of her daughter's demands.

3.4 The Fourth Case Study: Hadil

3.4.1 Introduction

At the time of therapy, Hadil was a fifty-nine-year-old married woman with four children. She met her husband, a qualified pharmacy assistant, whilst in her second year of training as a radiographer. They moved to Cape Town shortly after they got married. Hadil was engaged to her husband's brother, but broke off the engagement after she had become romantically involved with her fiancé's younger sibling.

As a middle child of ten children, Hadil described happy childhood memories as part of a loving, caring family. Her father worked as an informal trader and her mother was a housewife.

She had three sons and a daughter who were between twenty-three and twenty-nine years old. Other than her daughter, who had moved to her own home after her marriage, Hadil's three sons were still living at home.

All three of her boys became blind after they had developed *retinitis pigmentosa* (RP). Her eldest son, Yusuf, was diagnosed with RP at a young age and benefitted from placement in a school for visually impaired children. He qualified as a lawyer and contributed financially to the extended household. Her second eldest son, Ashraf, was diagnosed with mild ID. He also developed paranoid and disorganised behaviour during his adolescent years and was subsequently diagnosed with schizophrenia. Her youngest son, Ehan, had lost his vision eight months before she started attending psychotherapy sessions. He worked as a business analyst at a large corporation.

Hadil had chronic medical problems that included diabetes mellitus 2, hypertension and systemic lupus erythematosus. She told me she became clinically depressed

after her youngest son had been diagnosed with RP. She subsequently received psychiatric treatment for depression.

Hadil reported that her mood had improved with the use of fluoxetine, but she defaulted on her medicine when its reported sedative effects prevented her from completing some of her household tasks and responsibilities.

I interviewed Ashraf to obtain his consent about visiting the hospital while his mother attended therapy. Whilst working with him I observed auditory hallucinations and delusions of persecution. His mother also described increased aggressive behaviour, heightened irritability and lowered frustration tolerance. Ashraf's physical aggression was generally directed towards his mother.

He was also wandering around the neighbourhood looking for a girl who he believed was an Indian goddess. His mother was concerned about Ashraf's personal safety when he was walking alone in a neighbourhood with high levels of crime.

I referred Ashraf to psychiatry and he was admitted to hospital after his mother had attended three sessions. He was later discharged while his mother was still in therapy.

3.4.2 Case formulation

3.4.2.1 Predisposing factors

Hadil's early childhood experiences and positive recollections of a harmonious, supportive family system led to the development of beliefs that family members should always support each other, especially in time of crisis. Her beliefs were based on notions of mutual trust, family connectivity and self-sacrifice. Hadil also told me that her mother placed her children's needs ahead of her own.

However, at the time of therapy, Hadil experienced regular intervals of tension and conflict with her eldest son, Yusuf:

Hadil: And, uh, then he'll be very cross with me: *"I tell you but you don't listen to me!"* And I try and avoid that, because he's not Ehan; he's not Ashraf! He's a very rude child! I think he's a very angry child!

She also described a general lack of support from her extended family. Her sons required high support needs because of their sensory problems, but her husband had withdrawn from his family after Ehan's recent diagnosis of RP. In addition, her extended family expected her to provide full time care for Hadil's frail mother-in-law. Hadil stated that she felt unappreciated, disrespected and used.

She continued to provide caregiving in an almost stoic manner, but repeatedly stated her unhappiness and resentment towards her extended family for their lack of caregiving support.

3.4.2.2 Precipitating factors

Her youngest son's abrupt loss of vision eight months before the onset of psychotherapy precipitated elevations in parental stress and maternal depression. Hadil had to come to grips with the loss of a healthy child and her husband's subsequent withdrawal from the family. The following excerpt provides a glimpse of Hadil's efforts to come to grips with her son's loss of vision:

OC: Has it only been eight months?

Hadil: Yeah, it's recent, very recent. That's why we're still hurting . . . (tremor in voice; speaking softly) That's why we're still hurting.

Ashraf also started to display odd and bizarre behaviour which she did not understand.

3.4.2.3 Maintaining factors

Hadil's parental stress, feelings of exhaustion and depressive symptoms were maintained by a compounded caregiving burden; she also carried a heavy domestic workload with many family responsibilities. She got up at four o'clock in the morning and went to bed late at night. Hadil held two part-time jobs and prepared most of the family's meals. She took her two sons to work each morning during rush hour traffic and fetched them in the afternoons. In between, she also provided transport for her eldest son during the day. Yusuf's work as a lawyer required him to attend court cases at different magistrate courts across Cape Town:

Hadil: I get up to pray and then I take . . . first take a shower. Get up to pray; and then I prepare the lunch, breakfast for everybody. And then I, uh, Ehan is already in the shower; then I go drop him; come back; decide what we're gonna cook; see my mother-in-law is okay; she had a . . . My mother-in-law is also there with me. If she's eaten, she's hasn't eaten, warm her food again, but I make it early . . . And then Yusuf will come: *"Mom, I have to go to court today. Will you drop me in town? Will you drop me in ** [suburb's name]?"*, or wherever. And then I say: *"Okay, but must I wait for you?"* He says: *"It won't be long. It's a quick thing; it's a postponement."* Then I take him, most times . . . I wait four hours in the car.

I believe that her fatigue, insomnia and depression were most likely maintained by chronic medical conditions. Depression is common among individuals diagnosed with lupus erythematosus (Palagini et al., 2013). The psychological impact and

intrusiveness of a disease which affects numerous organs had implications on Hadil's energy and ability to cope with parental stress and depression.

In addition, diabetes mellitus has associations with stress and depression (e.g., Karlsen, Oftedal, & Bru, 2011; Shah, Gupchup, Borrego, Raisch, & Knapp, 2011).

3.4.3 Narratives of psychotherapy sessions

Session one

The first session was used to assess for psychotherapy and obtain applicable background information. Hadil's presenting problems were identified and contextualised. She confirmed elevated levels of parenting stress and depression. Moreover, she told me that she felt sad and helpless each time her youngest son struggled to complete activities on his own.

Hadil became tearful when I asked her about her parental experiences regarding the time when her children were diagnosed with RP. She stated that she regretted having more than one child and recalled that medical professionals were unable to diagnose RP in all three of her children. As a mother she felt responsible for "giving them their blindness because I gave birth to them". She believed she was "at fault" despite the fact that she had no idea that her children would develop RP until they were older.

Hadil described feelings of exhaustion and a longstanding history of insomnia. She also provided the following information: First, she confirmed a conflictual relationship with her eldest son. Second, her parental stress was not only maintained by her youngest son's adjustment to blindness and conflict with her other son, but also by Ashraf's behavioural difficulties. Hadil realised that something was wrong with

Ashraf because he was increasingly irritable with displays of aggressive and odd behaviour. She was worried about the poor quality of care that he would receive should he be admitted into the acute section of the hospital where I worked:

Hadil: (laughs) Ja, no, this isn't a lovely place. And, uh, uh, I get irritated when I visit him and the place smells like pee.

Third, Hadil described physical health problems that were related to lupus erythematosus and diabetes mellitus. Last, she was also stressed about the cost of Ehan's private healthcare and numerous outstanding medical bills.

Hadil's BDI-II scores were in the severe range of depression and she gave ratings of between 80 and 100 for negative mood, guilt and parental stress. We agreed to pursue the following therapeutic goals:

- Significant reductions in parental stress.
- Significant improvement of her negative mood and reductions in her sense of helplessness.
- To reduce self-blame and excessive feelings of guilt about her sons' RP.
- To improve her management of Ashraf's aggression and psychiatric symptoms.

Session two

Hadil gave maximum ratings for mood and parental stress. In contrast, her BDI-II scores came down from severe to mild depression.

She attributed her high subjective rating of negative mood and parental stress to the feedback she had received from a psychiatric registrar. I arranged this appointment

after I had observed symptoms of psychosis during an interview with Ashraf to obtain his consent for research. Ashraf disclosed some of his beliefs about a Hindu goddess who he had seen in their neighbourhood. He also insisted that she was recently hospitalised. Hadil told me she was shocked and saddened by the registrar's confirmation of Ashraf's psychosis; she also felt reluctant to follow his advice of having Ashraf admitted to hospital. She put Ashraf's mental health problems on the agenda. We used guided discovery and imagery to identify a number of negative automatic beliefs about her parenting and Ashraf's well-being whilst her son attended the psychiatric appointment:

Event: Sitting in the psychiatric registrar's office and listening to feedback which confirmed the presence of psychiatric illness.

Automatic beliefs: I should have picked this up! What if Ashraf go out looking for this girl? What if he gets hurt?

Emotions: Shock, guilt, apprehension.

Behaviour: Asking Ashraf questions about the Indian goddess.

Hadil stated that she was *"not a good enough mother"* for failing to pick up her son's psychiatric illness and subsequent distress. She also inferred that Ashraf's odd behaviour and aggression were forms of acting out against her parenting. For example, Hadil told me that Ashraf's recent episodes of aggression were most likely related to her earlier refusal to allow him to eat ice cream.

Hadil came across as a pragmatic, intelligent and articulate person. Her lack of knowledge about schizophrenia, which she described as *"two people who live in one"*, came as a surprise. I thought that she was either inadequately informed about the severity of her son's psychiatric condition or she was in denial as to what was

causing his behaviour. I provided basic psychoeducation about schizophrenia by describing the symptoms, biological base and treatment. Ashraf's behaviour was linked with grandiose delusions and I challenged her beliefs that she should have realised that he was psychiatrically ill. Cognitive disputation sought alternative explanations why she failed to recognise her son's illness. We discussed the complexity of ID dual diagnoses in concrete terms and the need to employ different diagnostic criteria to augment conventional classificatory systems. The psychiatric registrar who had assessed Ashraf previously had also failed to diagnose psychosis. There were indications that Ashraf was guarded about his beliefs, especially towards his family, who likewise did not know what was wrong.

Hadil reported that she felt considerably less guilty after we had disputed her beliefs that she was to blame. She then self-disclosed important personal information twenty minutes before the end of the session: she believed that she was "cursed" by her husband's brother after she had broken off her engagement with him:

Hadil: And he always told me . . . I never told anybody; you're the first person I'm telling. . . . And he always told me, you know? I know I tell him. And I didn't want to tell him I'm not in love with . . . I said: "*You know, this is just not gonna work out and I'm not in love with you and . . .*" (tremor in voice) He says: "*Well, whoever you marry, you won't be happy, because I know you love me.*" So I told him: "*I used to, but not anymore. I don't know why I don't like you anymore.*" And then he says . . . he told me like: If I have children, I'll have . . . all my children will have problems. So I said: "*What kind of problems?*" So he said: "*You'll see.*"

Feeling responsible and guilty about her children's RP, Hadil linked their illness with the events which had occurred thirty-eight years ago. These beliefs resulted in Hadil visiting her brother-in-law's grave in the past:

Hadil: ". . . *why did you curse me? Please take it back!*"

Session three

Hadil phoned earlier in the week before the third session to tell me that she was held at gunpoint and robbed. Her wallet and a valuable, borrowed handbag were stolen. Hadil did not have enough money to replace the handbag and was avoiding the disclosure of the unfortunate event to her friend.

In contrast to her earlier confusion and self-blame about Ashraf's behavioural outbursts, Hadil made the decision to have Ashraf admitted to hospital "because he was ill". She also stated that she was concerned about possible sexual abuse after Ashraf had told her that he was inappropriately touched by another user.

Despite the traumatic events and worry about Ashraf's well-being following admission, the symptom rating for depression came down from 100 to 50; BDI-II scores also measured in the mild range of depression. Her parental stress received a maximum rating of 100.

The first part of the session was used to ascertain whether the traumatic incident led to an acute stress reaction. Close-ended questions confirmed recurrent recollections, nightmares and continued sleep-deprivation. Yet Hadil told me that she was feeling much better; her abovementioned responses to the event were also becoming less pronounced. I was impressed by her resilience: Hadil went to the police to open a case of theft and continued with her daily tasks and caregiving

responsibilities in a mind-over-matter manner. We briefly focused on behavioural rehearsal to prepare her for the conversation with her friend about the stolen handbag.

Hadil also requested that we discuss her concerns about Ashraf's safety in the hospital ward. She was frustrated by the unwillingness of the nurses to place Ashraf in a single room at night to prevent future incidents of a similar nature. She was also upset about the manner in which some of the nurses responded to her telephonic enquiries about Ashraf's well-being:

Hadil: But what else do they take when they . . . this nurses? Because when I asked yesterday . . . when I asked the nurse: *"Are you sure he's sleeping on his own?"* So she doesn't know I understand Xhosa, so she said: *"Are you mad woman, or what?"* So I tell them in Xhosa again: *"I understood everything you said."*

OC: Mm. What did she do (then)?

Hadil: She told me: *"Now (inaudible segment), are you sure?"* I think I asked her too many times. I said: *"Where is he?"*

OC: Mm.

Hadil: So she said he's sleeping. So I said: *"Are you sure he's sleeping alone?"* So she said: [quoting in Xhosa] And she said, cause she said: *"Does she think I'm mad?"*

We discussed the possibility of lodging a formal complaint about the treatment she had received. Hadil was worried about the outcome of such a process and described the following double-bind:

Hadil: But that means they'll never see to him again should I need them!

She was also distressed and upset with her husband after he rebuked her for confronting a nurse about Ashraf's complaints that he had to share a toothbrush with other service-users:

Hadil: So I said: *"No, I am asking you a question, I'm expect(ing) you to answer me."* Then my husband said: *"No, why are you asking questions like that? You're gonna make her cross, then she's gonna take it out on Ashraf."*

Hadil's efforts to address unacceptable caregiving practices were therefore accompanied by worry and fear that she would antagonise the hospital system against her son, thereby limiting his future access to the service.

Session four

The session was more stilted and less productive than previous sessions. Parental stress remained elevated at 80. While her BDI-II scores stabilised in the mild range of depression, her subjective rating of depressed mood was given a higher ranking of 70.

She told me that she wanted to forward a humorous and light-hearted email she received to Ehan. She realised that Ehan would not be able to share the joke because of his blindness. She then thought about Ashraf's hospitalisation and she felt guilty and sad:

Hadil: And after laughing, watching it I went to bed, and I was still laughing. But then I thought of Ashraf and I thought: *I'm sitting here and laughing . . .* And I felt so sad.

Hadil's graphic description of her subsequent actions painted a picture of despair:

Hadil: I cried . . . and I got out of my room and I went into my bathroom. And I . . . and . . . That's how I normally feel better. Undress, sit under the shower, sit flat on the ground; hook my legs . . . (tremor in voice) and cry . . .

We identified a cognitive distortion behind her feelings of sadness and guilt: *I should not be laughing and happy while my children are unhappy.*

Her distressed reaction felt inherently valid as a normal response of sadness and grief in response to her youngest son's loss of vision. Our focus was therefore more on supportive work to process her feelings of loss. Hadil felt better the next morning after she realised that there were ways of sharing the joke with Ehan:

Hadil: But this morning it was much better, because I also thought: *Okay, I see this; Ehan can't see this.*

OC: [cross talk] Ah!

Hadil: *But I can tell him what's it about.* And I told him what's it about. And he also laughed. He said: "It must've seem funny, isn't it, mom?"

Following our last discussion, Hadil engaged with the hospital in an assertive manner by insisting that Ashraf sleep in a single room. She also told me that she was confused by Ashraf's request that she should put a *bindi* on her forehead to prevent further harm from Hindu goddesses. We subsequently spent a short time discussing the positive symptoms of psychosis.

Without being able to check up on her son because of the hospital's visiting hours, Hadil continued to worry about his well-being. She received rather harsh treatment over the phone from a nurse:

Hadil: So he says in Xhosa: *"Call that fat thing!"*

OC: Oh, really?

Hadil: Ja. So I told him in Xhosa: *"That fat thing is my son."*

Hadil also recalled a telephone conversation earlier in the week. The nurse's tone of voice and sarcasm made Hadil doubt her decision to be assertive by getting Ashraf placed in a single room:

Hadil: And I . . . I asked: *"How is Ashraf?"* And she said: *"No, he's fine. And like you ordered, he's sleeping on his own."* I said, *"Thank you."* They make me feel like I'm a bully.

Session five

Hadil's symptom checks for parental stress (40) and depression (50) showed a downward trend and BDI-II scores ranked in the minimal range of depression. The psychometric assessment that was conducted after four sessions also indicated significantly lower levels of parental stress (PSI-SF = 113 from a baseline of 150).

It was noticeable that Hadil continued to describe longstanding feelings of guilt and self-blame about being somehow responsible for her children's RP. We therefore decided to focus on Hadil's negative automatic beliefs that led to sadness and guilt. She effortlessly identified a cognitive distortion and two core beliefs that were going

through her mind each time she witnessed her youngest son hurting himself against objects and furniture because of his blindness:

God is punishing me.

I am to blame.

I am at fault.

As described earlier, Hadil broke off her engagement with her husband's brother. His prediction that she would have problems with her children caused her emotional distress for almost thirty-eight years:

Hadil: It really feels like that! And then I . . . then I speak to God and I say:

"Please, I can't anymore! I'm getting old now! I can't anymore!" Why would he have said something like that? *"Marry my brother, and you'll see you'll have children with problems."* Maybe he didn't mean (it)?

She was never able to find out why he held such beliefs. As the years went by, all her sons were diagnosed with RP. Hadil blamed herself for passing on the "faulty genes".

We used Socratic dialogue and cognitive restructuring to address these beliefs. Hadil based her beliefs of being at fault on the fact that she was their mother and because of her brother-in-law's predictions. Evidence against the idea that she was to blame and at fault was based on repeated reassurance from medical specialists and geneticists. They told her that pre-emptive knowledge about RP would have been impossible. Hadil also told me that there was no genetic screening or medical testing to establish whether unborn babies had RP.

Session six

Hadil was visibly distressed when she rushed into the office more than two hours after our scheduled appointment time. She apologised for being “so very late” and asked whether it was possible to go ahead with the session.

When I asked her why she was so agitated, Hadil told me that she received a phone call from one of her brothers-in-law earlier in the day. He accused her of not paying enough attention to Ashraf and urged her to take better care of him. Ashraf was already spending his weekends at home and Hadil was informed about the intention to discharge him within the next two weeks. Her son remained psychotic although he was less thought-disordered and aggressive.

Hadil felt embarrassed and hurt by her brother-in-law’s criticism. Her symptom checks for depressed mood and parental stress were given maximum ratings. Yet her BDI-II scores, which also measured negative symptoms of depression and her mood over the past week, placed her depression in the minimal range.

Hadil: Ja, and then when he said that he doesn’t think that I’m not giving him enough attention it made me feel very guilty!

OC: Guilty?

Hadil: It’s making me feel very, very, very guilty.

She continued to worry about possible sexual abuse in the hospital ward. We briefly discussed the steps that were taken to prevent abuse including those which were already in place: Ashraf slept in a single dormitory; there were surveillance cameras in all the areas of the ward; during the day supervision was provided uninterrupted;

and Hadil also realised that Ashraf would most likely call for help if he was assaulted by another service-user.

Once we started to discuss her conversation with her brother-in-law it was noticeable that his criticism was based on his perceptions of Ashraf as a person with disability and special needs. It also became apparent that Hadil believed she was at fault for not providing enough attention to her son. She described herself as “*a bad mother*”.

I used basic psychoeducation to distinguish intellectual disability from schizophrenia. If her brother-in-law based his accusations on Ashraf’s needs as a “*special child*”, specific symptoms of psychosis would not be readily understood. Hadil indicated that she understood that she was not responsible for her son’s odd behaviour. She spoke openly about her feelings of anger and humiliation: she received little support from her family but they were quick to criticise her parenting:

Hadil: But I definitely . . . they must help me somewhere. Either with my mother-in-law . . . my mother-in-law is a full time job, I promise you. She’s a full, full-time job!

Hadil was invited to a wedding in Durban. She was worried about leaving her family in Cape Town, but I encouraged her to attend the wedding for the following reasons: She told me that part of her was excited about the prospect; she had already made alternative caregiving arrangements for her children; and I also believed that a break might give her some respite from her unrelenting caregiving responsibilities.

Session seven

Hadil attended psychotherapy for the first time in two weeks and reported significant improvements on symptom checks that measured parental stress (30) and depression (20). Her BDI-II scores continued to measure minimal depression.

Hadil stated that she used the circular diagram of the CBT model to problem-solve many of her family and caregiving stressors. She took the basic principles to heart and used the printout that was provided in the first session each time she was confronted with a difficult situation at home:

Hadil: And uhm . . . no, guilt. Ah, I think they try and make me feel guilty. But then I . . . I tell myself, and I go to my little chart, my granddaughter took it to their house. And I miss it, and I take that chart and I tell myself: *should I feel guilty?* They're trying to make me feel guilty, but why should I . . . I'm trying my best; I'm giving my whole self to my family! (Conversation in corridor discernible in background) I'm not keeping a wee-bit for myself! Maybe they should feel guilty that I'm giving so much of myself!

OC: Wow, that's a bit of a shift?

Hadil: A big shift!

OC: That's a bit of a shift, yes . . .

Hadil: Ja. I said look . . . their condition. I must help them to my . . . to them . . . to the best I can. And I know God will give me the strength to carry on! But if I'm going to be, uh, down and out . . . I'm not even gonna be of any use to them, let alone me!

She mentioned that she thoroughly enjoyed the wedding and her weekend away from home. When I asked her how she dealt with her feelings of guilt for leaving her family behind, Hadil's answered that she did not think it was constantly necessary to justify her caregiving decisions to family members and relatives.

Hadil: Ja, no . . . so that was that, but I said: You know what? Everybody is going to say something. I can't go to them and explain them: "*Look here, this is the story . . .*" I can't! It's how I feel. Fine if that's how you feel! Tough!

OC: Mm.

Hadil: It's my son, I'm trying my best. If you think it's not good enough: tough!

Her anxiety also lessened following Ashraf's discharge from hospital. Towards the end of the session, Hadil described another traumatic experience that had occurred a few years before. She rushed Ashraf to the emergency room of a large tertiary hospital after he had started to complain of chest pain. He was resuscitated and placed in the intensive unit of the hospital. Hadil's understanding was that Ashraf developed these symptoms as side-effects to medication.

In an angry tone of voice, Hadil went on to describe how a specialist re-assured her that her eldest son's blindness was because of complications at birth. He was reportedly misdiagnosed and it was only later that they found out Yusuf suffered from RP.

I believe that these earlier caregiving experiences shaped some of Hadil's beliefs about the need to be vigilant regarding her children's medical and nursing care.

Ashraf's recent admission, his subsequent sexualised behaviour and the indifferent

treatment he received therefore caused elevated levels of parental stress and anxiety.

Session eight

BDI-II scores ranked in the minimal range of depression and Hadil's symptom checks also measured lower when compared with earlier sessions (depressed mood = 20 and parental stress = 40). Improvement across different measures of subjective well-being allowed us to discuss termination. With this in mind, we decided to focus on ways of managing future caregiving challenges, including the need to be assertive towards her nuclear family and relatives.

Hadil repeatedly told me that she felt less guilty about past caregiving incidents:

Hadil: And it feels so much lighter, I can . . . I can . . . I felt guilty, man! I felt guilty, I thought: everything is my fault! And man! I feel better now, uh, the kids, okay, I don't think it's God's will . . . maybe it's my test. Maybe there'll be something better for me in . . . next time. But right now it's my test, and God has given me this test and I must prove to God that I'm going to do it the way He wants me to do it.

She also told me that she was becoming more assertive towards family members. When her relatives from up-country visited her unexpectedly earlier in the week, she told them that she was not able to see them because she had to fetch her youngest son at work:

Hadil: Yeah. It's like in me . . . like I have to do. . . . Like somebody came, uh, came yesterday . . . home . . . but I . . . I . . . I've never, ever, ever, ever done it in the past and I genuinely was going to fetch Ehan.

Hadil started to prepare meals for her family in bulk to reduce the number of hours she had to spend in the kitchen. This allowed her time to attend her granddaughter's ballet concert:

Hadil: That make a little extra food, tomorrow you're going to [granddaughter's name's] concert, so you have time to go to her ballet. So I just make a little extra food and then I go to the ballet, like yesterday. I went . . . *"No Granny, would you please go to the ballet?"* The kids said: *"Oh, eating the same food again?"* I said: *"Tough! That is what we're serving today!"*

Despite her increased assertiveness, Hadil continued to feel somewhat guilty that she spent less time in the kitchen. We modified imperative thoughts that nutritious meals should be prepared every day by recognising her limited support from family members and relatives. For example, if her relatives criticised her for not preparing meals from scratch for her mother-in-law, she could legitimately ask why she was tasked to provide all the caregiving for her mother-in-law.

Hadil also stopped assisting her eldest son with transport and domestic support. Despite my reservations about the fact that they were essentially ignoring each other, Hadil's reasons for refusing to help her son with some of his daily activities were clear:

Hadil: . . . I can't believe I'm telling you this. I-I-I think I'm too ashamed to tell it to anybody else: I've never felt so happy! He doesn't ask me for anything. If he wants an egg, he'll try and find it and do it himself. If he wants the phone, he can't see if the phone is on the bed . . . it's supposed to be on the cradle. So it's on the bed by me. He will go to the cradle and he'll ring it . . .

OC: Mm.

Hadil: . . . to see where's it. And he'll hear and he'll fetch it. I won't even say:
"Here's it!" I'll leave him. It's never been like that.

OC: Why are you happy about it?

Hadil: No, I-I-I feel he doesn't bully me. He doesn't abuse me anymore. (pause)

Session nine

Symptom checks for depressed mood (20) and parental stress (40) continued to measure at lower levels. BDI-II scores measured in the minimal range of depression.

Hadil highlighted the benefits of learning more about Ashraf's psychiatric illness. She also mentioned that she gained more knowledge about herself. She no longer believed that Ashraf referred to a real person when he spoke about the girl in their neighbourhood, but realised that his fixation on the reincarnated Indian goddess was caused by his psychosis. She also lowered her expressed emotion and stopped blaming him for not going to the mosque, because she understood his avoidant behaviour as the result of persecutory delusions:

Hadil: But look, before I used to get angry when he refused to come, but now I do realise he's sick, so I do invite him, but I don't get cross anymore.

OC: [cross talk] Mm. Mm. Mm.

Hadil: I don't put up a big squeal, you know? I used to squeal before: *"But yes, you don't want to think about God and this and that!"*

I believe that knowledge about Ashraf's illness led to changes in their interaction which facilitated an improved parent-child relationship. Post-assessment psychometric scores describe significantly lower levels of parental stress.

Some of our discussion focused on the future and the prognosis of schizophrenia. Hadil was worried about what will happen to Ashraf after her death. She told me that Ashraf's brothers were embarrassed by him. She was also worried that their future spouses, should they marry, may not accept Ashraf and allow one of the brothers to become his primary caregiver.

Ashraf's siblings had also repeatedly told her that they will not take care of him after her death.

Hadil was visibly emotional during this discussion. She felt hurt by her other children's treatment of her second eldest son. It left her with a desperate and powerful wish:

Hadil: I hope he dies before I die. Even if it's a day before I go. So that I can die in peace!

3.4.4 Interview after psychotherapy had been terminated

Hadil provided positive feedback about psychotherapy. She realised that she had to start pursuing her own interests and be assertive towards her family. She also told me that she was coping better and that she felt "stronger" to face adverse caregiving events.

Hadil's mood improved significantly from baseline. The excerpt below describes Hadil's experience of therapy in her own words:

Hadil: You have to work at it! You have to work at goals. If you're gonna just take what you get, it's never gonna come right. And that's what I've been doing all my life. Is ah, oh . . . my sons can't see. And feeling sorry for them, instead of . . . You've taught me to help them . . . how to help them by being there for them. I used to be there for them. But I should be there for them. . . . I always used to be sad. And now with me, I can see my kids are also becoming okay. They are smiling and-and they see me happy, so they're also happy.

Hadil repeatedly referred to the need to engage with her caregiving challenges; to seek solutions; to persevere. She also told me that she learnt more about Ashraf's behaviour and ways of managing it. In addition, she also felt much more hopeful about the future and increased hopefulness was correspondingly measured on the Hope Scale.

Thus, the resolution of depression energised her; and she had an enhanced capacity to deal with adverse caregiving events. However, she continued to experience Ashraf's psychosis as disturbing and unmanageable.

3.4.5 Themes that emerged from thematic analysis

Theme	Excerpt
The impact of compounded caregiving challenges and responsibilities: Conflict with her eldest son and parental stress about her children who do not have ID.	<p>Hadil: And, uh, then he'll be very cross with me: <i>"I tell you but you don't listen to me!"</i> And I try and avoid that, because he's not Ehan; he's not Ashraf! He's a very rude child! I think he's a very angry child!</p> <p>Hadil: I said I thank God. I said: <i>"You know what, I'm sorry that Ma's sick, but I think this was the right time to move off, because what if he was in the water and he got hurt? What if we were walking this way and he got hurt?"</i></p>
Parental stress that was brought upon by Ashraf's aggression, mental illness and his high behavioural support needs	<p>Hadil: Last night, I must have slept for about ten minutes, if you call that sleep. My husband asked me on a few occasions: <i>"Hadil, what's the problem? Why aren't you sleeping?"</i> So I told him. I said: <i>"You know what, I am so worried about Ashraf. Can't we just keep him at home? I'll cancel this trip."</i></p> <p>Hadil: But uh, it's . . . I don't know . . . like this morning now coming here and I said: <i>"Ashraf, I asked you to bath three times, you said . . ."</i> I saw him in the shower.</p> <p>OC: Mm.</p> <p>Hadil: But he didn't bath clean. So he said: <i>"Ag, it doesn't matter!"</i> But it matters to me! It upsets me, and I was very cross in the car!</p>
"I am a bad mother": Guilt, self-blame, helplessness and hopelessness as symptoms of maternal depression.	<p>Hadil: I cried . . . and I got out of my room and I went into my bathroom. And I . . . und . . . That's how I normally feel better. Undress, sit under the shower, sit flat on the ground; hook my legs . . . (tremor in voice) and cry . . .</p> <p>Hadil: And after laughing, watching it I went to bed, and I was still laughing. But then I thought of Ehan and I thought: I'm sitting here and laughing . . . And I felt so sad . . . I felt really sad, you know? I thought: Why am I laughing? Why am I</p>

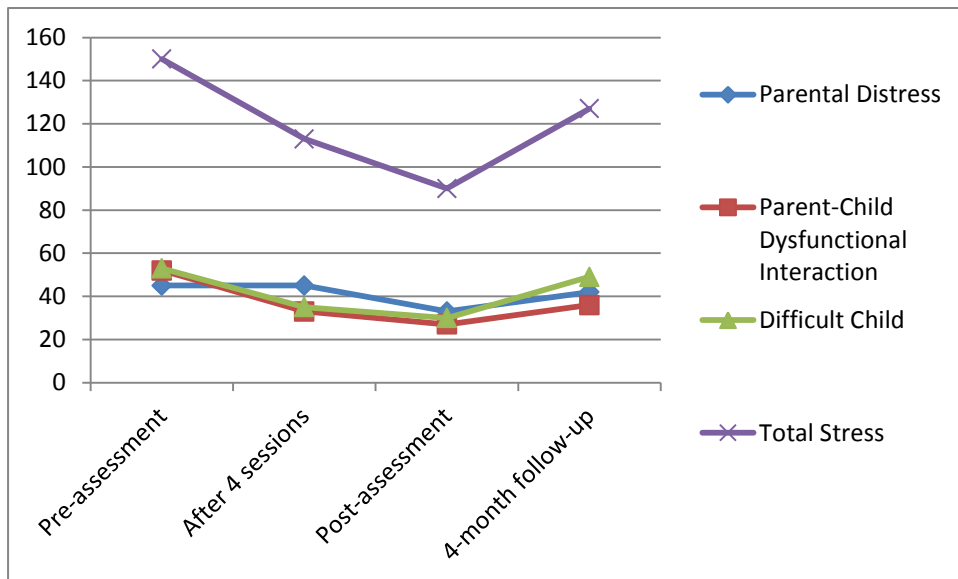
	<p>so happy when my son is here?</p> <p>Hadil: No, I felt terribly guilty. Although he tried to tell me: <i>"Look, it's not your fault!"</i> But I deep down knew it's my fault! Up to today I keep on blaming myself. I don't know why!</p> <p>Hadil: I used to feel bad. I used to feel I'm a bad mother.</p>
Grief and loss of a healthy child following Ehan's loss of vision	<p>OC: Has it only been eight months?</p> <p>Hadil: Yeah, it's recent, very recent. That's why we're still hurting . . . (tremor in voice; speaking softly) That's why we're still hurting.</p>
Conflict and sadness about a lack of support and unjustified criticism from relatives to support her with compounded caregiving responsibilities.	<p>Hadil: <i>"I am trying my best, but don't you think I need a little family support?"</i> I asked him. And you know my mother-in-law is in hospital? She's in the hospital; she's in the intensive care. She's got the best care, but I'm expected to go take her meals three times a day, because she doesn't eat the hospital food.</p> <p>Hadil: I did tell him: <i>"I wish you guys could support me a little bit! It's Ashraf; Ehan and Yusuf!"</i></p>
Financial strain	<p>Hadil: Okay, if finances . . . it's also a problem, but, uh . . . but if you can . . . if you could help . . . I don't mind working all the time paying off my credit. I don't mind taking credit even. I hate credit, but taking credit if I can help my kids!</p> <p>OC: Mm.</p> <p>Hadil: But it's not helping! I'm still in this black hole but it's not helping. (Long pause)</p>
Standing up for herself: Increased assertiveness towards family members and relatives	<p>Hadil: Ja, no . . . so that was that, but I said: You know what? Everybody is going to say something. I can't go to them and explain them: <i>"Look here, this is the story . . ."</i> I can't! It's how I feel. Fine if that's how you feel! Tough!</p>
Dissatisfaction and anger about formal health support services	<p>Hadil: If he wants the . . . he told me I'll chat just now. If he tell me . . . I got him while waiting for you and he said: <i>"I'll chat just now."</i> So I told him I've got an</p>

	<p>appointment with you. So he said: <i>"I'll chat just now."</i> So I'm not going go look for him.</p> <p>OC: Mm.</p> <p>Hadil: But the . . . I will want to know what he wanted to chat about.</p> <p>OC: Most likely about the issue of . . .</p> <p>Hadil: Yes, you know? He didn't want to speak to me! He said: <i>"Look, tell Hadil I only speak to parents on a Friday! I'll speak to her on a Friday!"</i></p> <p>* Please refer to cited dialogue in narratives involving Hadil's interaction with the nursing staff for additional examples of theme.</p>
<p>Caregiving through the decades: Ageing and the role of chronic medical conditions on Hadil's capacity to provide care</p>	<p>Hadil: I know when they told me I have Lupus, and uh, my sister-in-law said: <i>"Hadil, what... you don't look well."</i> So I said: <i>"I'm not feeling well, but for that whole two months I wasn't well."</i> So she said: <i>"Ag, jy bly siek!"</i> (Oh, you stay sick!)</p> <p>Hadil: I mean, look . . . I'm fifty-eight already. And uh, you... we don't live forever.</p> <p>OC: We don't.</p> <p>Hadil: We don't live forever and another thing is . . . uh, I'm getting . . . I also get . . . I get tired now. Now even when the kids ask me or when anybody ask me to do something. I say, you know what, I'm tired! I can't! I really can't!</p> <p>Hadil: There isn't a day that I don't feel sick, because of the tablets. I did mention it to my doctor, so he sent me for a gastro-scope [sic] and they found that I have, uh . . . I don't know what! An inflamed gut.</p>
<p>Examples: Cognitive distortions about parenting</p> <p>Cognitive distortions: imperatives and</p>	<p>Hadil: I am always perfect. I always... I</p>

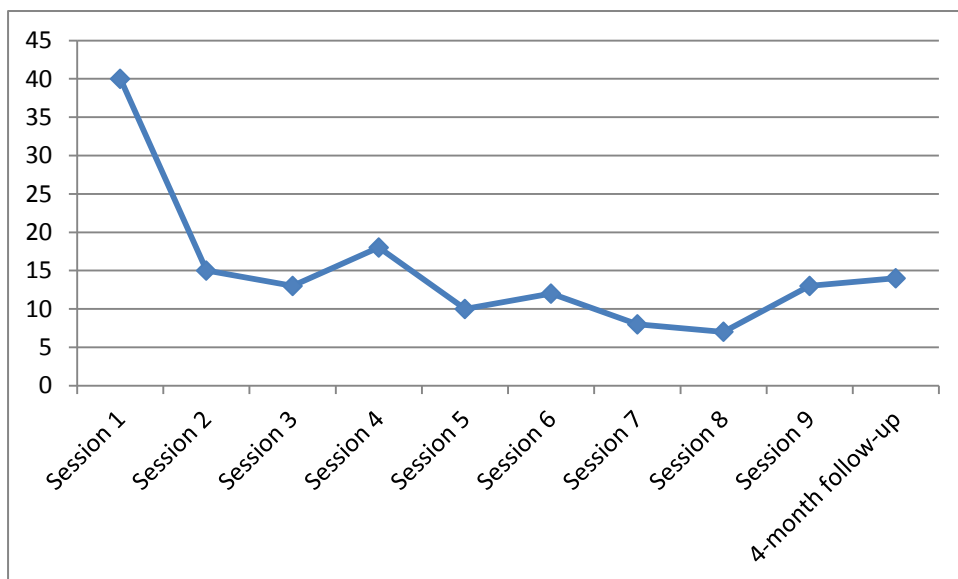
all-or-nothing thinking	am ... I always want to be perfect.
Cognitive distortion: personalization and overgeneralisation	<p>Hadil: I can . . . I can . . . I felt guilty, man! I felt guilty, I thought: everything is my fault!</p> <p>Hadil: You know, I just hated myself so much that I took blame for everything! My mother-in-law got sick, it's because of me; I couldn't give her enough attention!</p>

3.4.6 Psychometric test results

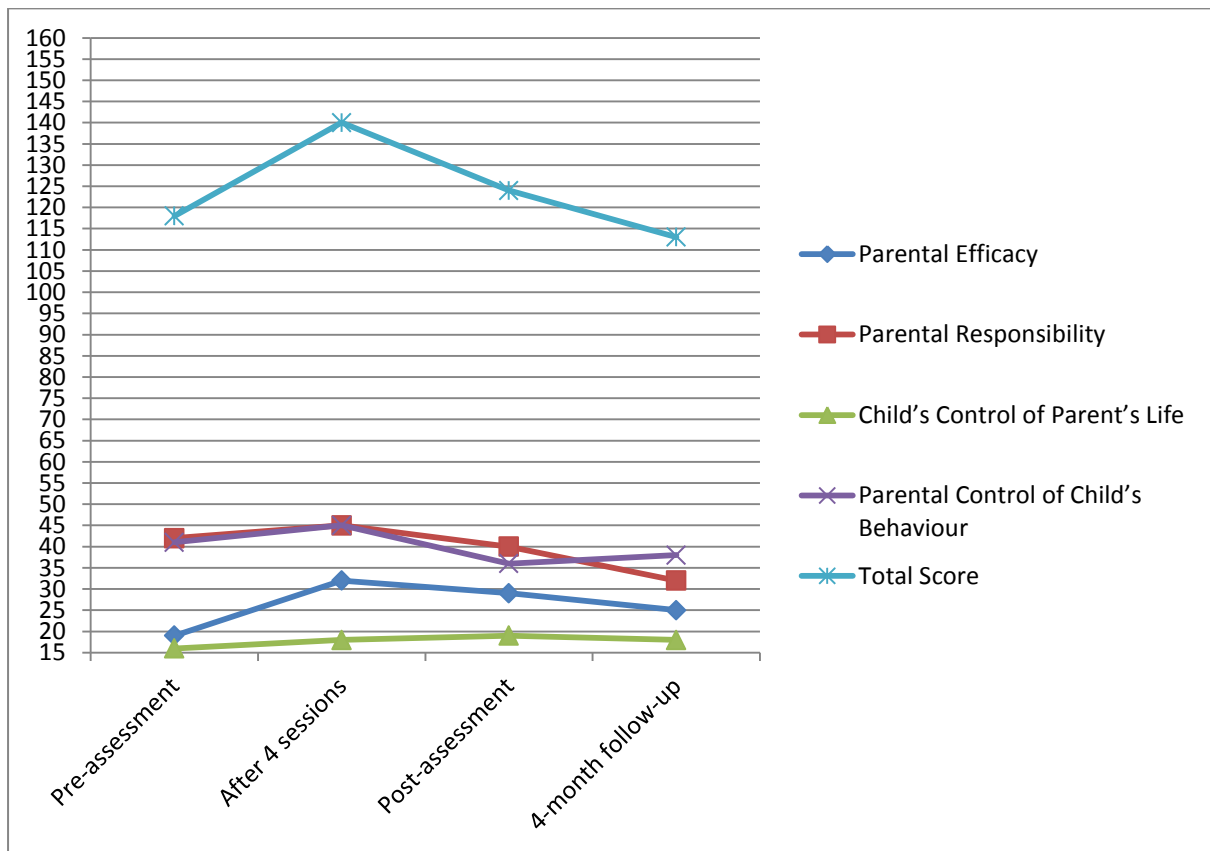
The Parenting Stress Index: Short-Form (PSI-SF)



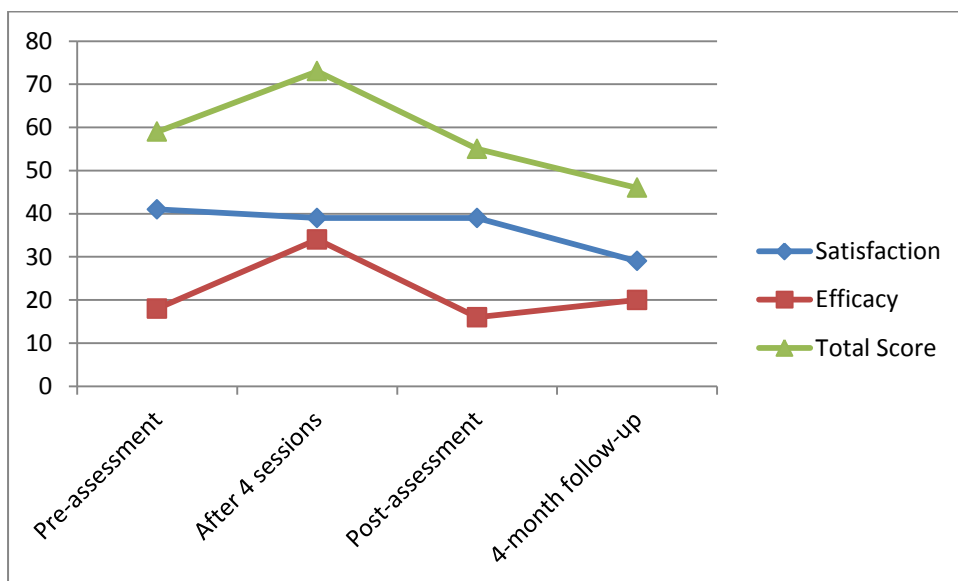
The Beck Depression Inventory-II



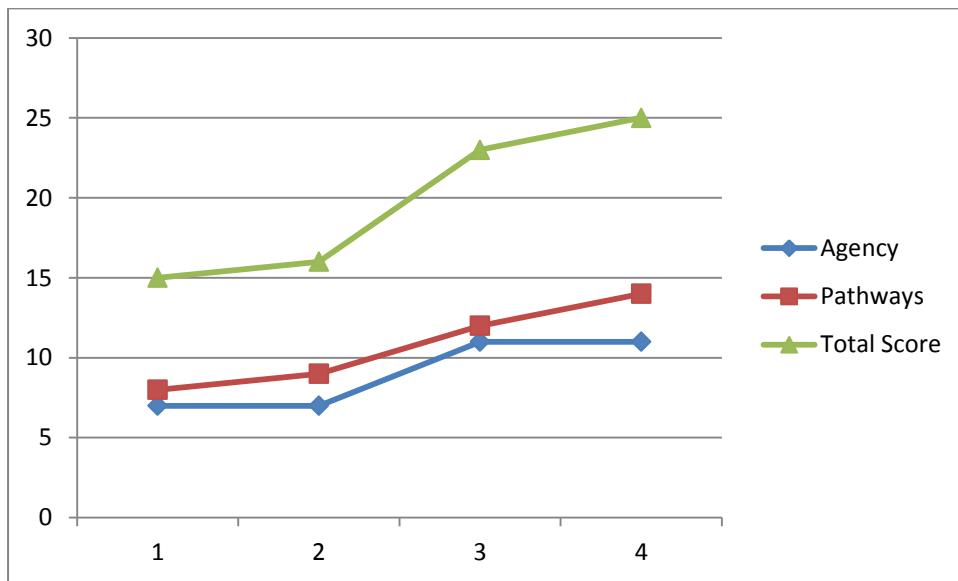
The Parental Locus of Control Scale



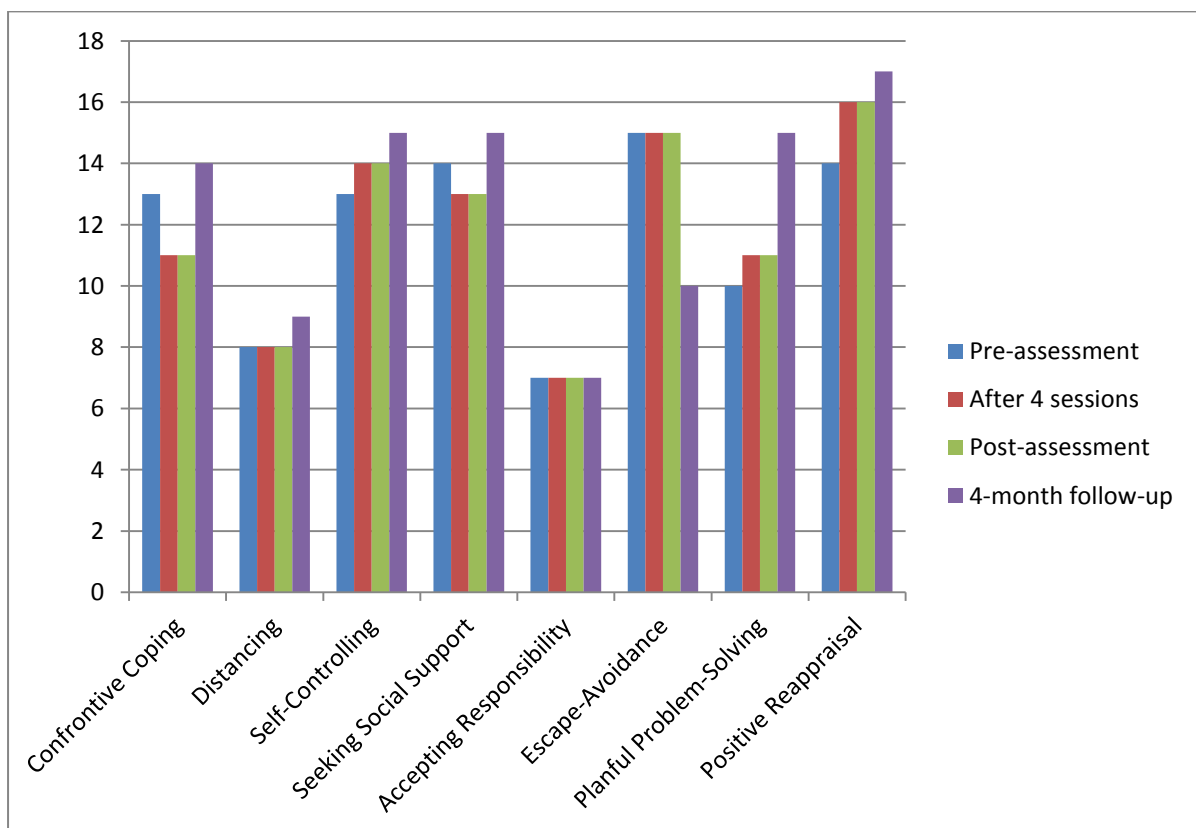
The Parenting Sense of Competence Scale



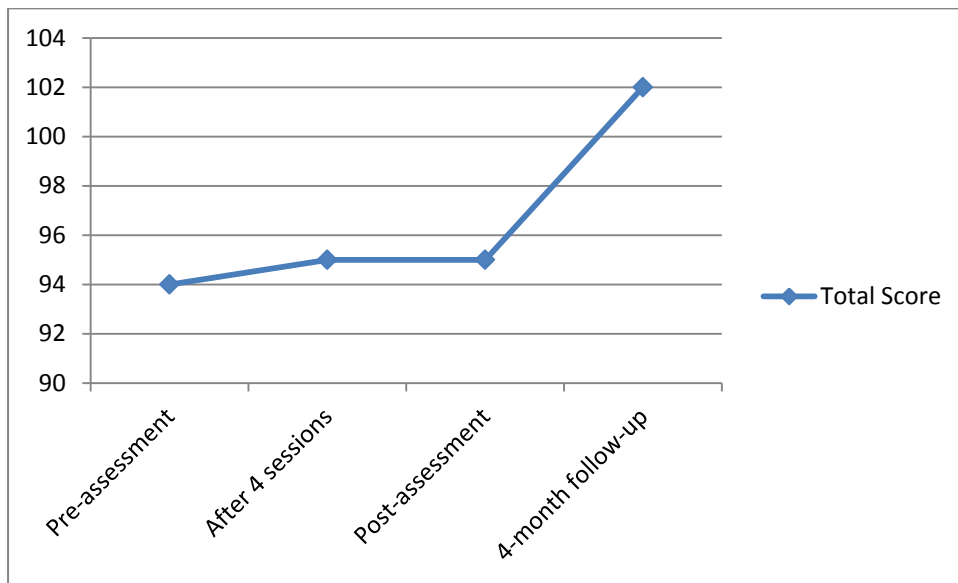
The Hope Scale



Ways of Coping Questionnaire: The Eight Ways of Coping



Ways of Coping Questionnaire: Total Score



3.4.7 Discussion

3.4.7.1 The usefulness of distinguishing Hadil's parental stress from depressive symptoms without discarding overlap between the two concepts

BDI-II scores and ratings on the Hope Scale were consistent with clinical observations and her feedback to suggest that Hadil's improved mood was sustained at follow-up four months after therapy had been completed.

Conversely, Hadil's lower levels of parental stress after nine sessions were not sustained at follow-up. The findings are significant in light of recent criticism in ID family research against the interchangeable use and conceptual entanglement of parental stress and depression (Hayes & Watson, 2013). Thematic analysis elicited possible reasons why Hadil was unable to sustain her gains with regard to parental stress:

First, Hadil told me that Ashraf continued to display aggression and other behavioural difficulties even though his psychosis was in remission. Second, her youngest son, Ehan, was retrenched shortly after therapy had been completed. Hadil was worried and *stressed* about her youngest son's psychological well-being after he had lost his job. Third, Hadil went into cardiac arrest and was admitted into intensive care some time before she completed follow-up assessment. She described chronic feelings of fatigue which I conceptualised as having a negative influence on her coping resources and ability to manage Ashraf's behaviour. She reported that she found it difficult to keep-up with all her caregiving responsibilities. Fourth, most of her kitchen utensils and catering equipment got stolen after burglars broke into their house. Last, she mentioned that her daughter was expecting a son. She was concerned and worried about the possibility that her grandchild would also have RP.

Following the scoring of tests after Hadil had completed follow-up assessment, I contacted her to ask her why there was a discrepancy between PSI-SF and BDI-II scores at follow-up. She indicated that she was able to remain more assertive towards family members; she also continued to feel less guilty and sad about past events. However, she was exhausted and worried about Ehan's unemployment and Ashraf's behaviour was difficult to manage. Her insomnia also continued to be problematic.

Although Hadil had described a gradual onset of depression years before her youngest son became blind, this traumatic event precipitated a marked deterioration in her mood. She grieved about her son's loss of sight; in a real sense Hadil also mourned the loss of a healthy child.

Psychotherapy covered some of these painful experiences during the earlier parts of intervention. Hadil also had time to renegotiate her relationship with her youngest child and come to grips with his loss of vision. Spontaneous recovery through the course of time may have contributed to her improved mood.

Psychoeducation provided some information about schizophrenia and the aetiological base of Ashraf's aggression. The challenges of managing severe aggressive behaviour remained in place and Ashraf's behaviour continued to be distressing and unpredictable.

It is noteworthy that Hadil maintained most of her gains on the subscale Parent-Child Dysfunctional Interaction in the PSI-SF. It is possible that her improved insight about Ashraf's aggression led to a less confrontational style of engagement between mother and child. As Hadil put it: *"I now understand my child so much better."*

Unlike many of the precursors which maintained her depression, enhanced controllability over Ashraf's behavioural difficulties and schizophrenia was much less attainable. In other words, I believe that Hadil's parental stress was largely maintained by Ashraf's mental illness, a biologically-driven and internal reinforcer of behavioural difficulties over which she had limited control. These observations are confirmed by the Parental Locus of Control Scale, which in fact suggested movement towards an external locus of control after four sessions before reverting back to scores that were similar to baseline measurements. Research has confirmed that parents of children who have mental illness often experience low levels of control, precisely because the causes of severe psychiatric disorder are largely neurobiological (Heller et al., 1997; Kim et al., 2003; Seltzer et al., 1995).

Although most of the items on the PSI-SF measure responses of perceptions pertaining to an individual child, some of the questions also deal with general parental beliefs. Examples include items such as:

"I often have the feeling that I cannot handle things very well";

"I find myself giving up more of my life to meet my children's needs than I ever expected"; and

"I feel trapped by my responsibilities as a parent" (Abidin, 1995).

It is conceivable that Hadil's parental stress became elevated after her youngest son's retrenchment. I specifically asked her to complete PSI-SF forms to reflect her parental stress as it relates to Ashraf's caregiving. However, the items that measure general parental beliefs could have elevated her PSI-SF scores if adverse events in the lives of her other children had an impact on her broader views of parenting.

Parental stress and depressive symptoms undoubtedly have considerable overlap: both phenomena are characterised by appraisals of helplessness; in Hadil's life the impact of reported chronic medical conditions, fatigue and exhaustion might have led to depleted coping resources which made it more difficult for her to deal with parental stress and depressive symptoms such as her feelings of sadness and guilt.

Notwithstanding the overlap, it is useful to distinguish the broader aetiological base of depressive symptoms from parental stress, which in this case study was closely linked, amongst other parenting challenges, with Ashraf's behavioural difficulties.

3.4.7.2 Hadil's guilt and self-blame

Hadil's symptoms of depression included sadness, fatigue, a lack of enjoyment in activities that were previously enjoyed, insomnia and hopelessness. I have also described Hadil's feelings of guilt and self-blame as a central theme of the case study.

The cognitive theory of depression holds self-blame as a prominent feature of depression (A. Beck & Alford, 2009); and excessive guilt is described as one of the core symptoms of major depression (APA, 2013).

Hadil's beliefs of self-blame were based on schemata of being defective and contaminated. As described earlier, Hadil and her husband underwent extensive genetic testing. Geneticists eventually informed her that both families might have shared a genetic condition that led to RP.

Hadil told me that she blamed herself for carrying the defective genes that were responsible for her sons' blindness. She also blamed herself for having a third and

fourth child even though she was unaware that her eldest son had RP when she fell pregnant with Ashraf and Ehan.

I also described Hadil's interaction with her fiancé after she had broken off her engagement more than thirty-eight years ago. The fallout left her with unfinished business and questions whether her children were somehow "*cursed*" by him.

Because she went on to marry his brother, Hadil often wondered whether he was privy to information about a possible genetic vulnerability within his family. However, Hadil had asked him about this at various times. There was no evidence to suggest that he had any knowledge of predisposing risk factors in his family.

Hadil's feedback suggests that psychotherapy reduced her feelings of guilt; therapy also enabled her to renounce the possibility that her children's blindness was the direct result of her brother-in-law's perceived anathema.

3.5 The Fifth Case Study: Marlene

3.5.1 Introduction

At the time of therapy, Marlene was a fifty-four-year-old married woman with two children, Karin (24 years old) and Leon (28 years old). Her children were born from a previous marriage. Marlene worked as a qualified nurse at a private hospital. She was in poor physical health and suffered from systemic lupus erythematosus and asthma. She experienced breathing difficulties that were exacerbated by her status as a heavy smoker. Marlene also had a minor stroke two years before she attended psychotherapy.

Her daughter was diagnosed with mild ID, cerebral palsy and bipolar mood disorder. Karin's manic episodes were characterised by increased irritability, impulsivity, argumentativeness and episodes of physical aggression. During such times, Karin got along with very little sleep. Her ritualised packing and unpacking often continued throughout the night.

Marlene had experienced extensive emotional, physical and sexual abuse during her previous marriage. Her first husband, the father of her two children, threatened to kill her if she did not marry him. In an unprecedented disclosure, Marlene also told me that she was raped by her husband before they got married. Karin was born prematurely six months into her pregnancy after her first husband had physically assaulted her. Marlene believed that the incident was responsible for Karin's ID. She also had two miscarriages in their marriage as a result of physical abuse. Marlene eventually divorced her husband because of the persistent physical, sexual and emotional abuse. The marriage lasted sixteen years. Marlene stated that she continued to see her ex-husband on occasion when he visited her children at home. She added that she had processed her trauma and that his visits did not upset her.

Marlene's second husband was unemployed. He was dependent on alcohol but she described him as a source of support and a good companion.

Marlene was part of a large family. She was a middle child and had twelve siblings. Her family's socio-economic circumstances deteriorated after her father had an accident while he was at sea. He was a sailor and the incident forced him into early retirement. As the sole breadwinner, his loss of income sent his family into absolute poverty.

Marlene recalled childhood memories of being teased by other children because of her ragged clothes and the welfare support their family received from the church. Yet as a staunch Catholic her father impressed on her the value of family. Marlene had received extensive family support from her brothers and sisters in recent times. They continued to assist in Karin's care. She told me that help was never more than a phone call away.

3.5.2 Case formulation

3.5.2.1 Predisposing factors

As I will illustrate in the narratives, her sensitivity towards criticism from her eldest son and the concurrent episodes of conflict were embedded in core beliefs that developed from experiences in childhood and the early years of her first marriage.

Marlene was in primary school when her father became unemployed. Faced with physical disability and the shame of being dependent on others to provide for his family, Marlene told me that her father lapsed into substance abuse. She became a *"tomboy"* to defend her siblings from other children's antagonism and bullying.

Although she loved him dearly, Marlene also indicated that her father sometimes lashed out at her until there were "red marks".

Although her father had reservations about her fiancé, she did not disclose the sexual abuse or rape to him or other family members. She also mentioned that her aunt and mother often treated her differently to other siblings; and she recalled episodes where other children would receive luxuries when she did not:

Excerpt 1:

Marlene: It's in . . . yes, she lived and then she was the one more for my sister, you know? My sis . . . then my sister went with her to ** [town's name] but anytime we got holiday weekends she . . . so I was the one that was left out all the time.

Excerpt 2:

Marlene: I think I was hurt (by) them so . . . me so much, I think I wasn't really part of the family (crying).

Her resistance in the face of adversity was remarkable and she persevered to qualify as a nurse. At the time of therapy, Marlene had been employed for over thirty years. She was able to maintain her core function as mother and breadwinner notwithstanding years of abuse and IPV.

Although her resilience was undoubtedly protective, she stated that her childhood experiences left her with a sense of inferiority. She told me that she worked through many of these issues by attending courses to become a counsellor.

As with her earlier trauma, in the years of her first marriage Marlene maintained "*a brave face*" to the world without disclosing her husband's abuse to her siblings or friends. She was hospitalised and treated for depression during her first marriage before her children were born. At the time of therapy, Marlene often laughed

following disclosures of painful events. I got the impression that she continued to minimise the distressing impact of traumatic incidents that occurred earlier in her life.

As part of the cognitive conceptualisation that I formulated to plan treatment, I tentatively considered the impact of Marlene's earlier experiences as follows: First, it is conceivable that Marlene developed fundamental beliefs that she should be able to cope with adversity on her own and without the help of others; second, that as a child and young adult she perceived herself as vulnerable, alone and unsafe, and last, that especially the male figures in her life could not be trusted:

Marlene: I don't know, maybe I'm . . . I never trusted people about my feelings.

OC: Mm. Mm.

Marlene: Like that: I think I never trusted people.

OC: Ja?

Marlene: I never trusted family, like I said to you...

Besides her first husband and father, as a child Marlene was also fearful of her eldest brother.

3.5.2.2 Precipitating factors

About two years before the onset of psychotherapy, Marlene was forced to resign from work in order for her pension to be paid out. This radical step was taken to nullify arrears on her monthly bond instalments. She was appointed as a nurse at a private hospital. Marlene said that she missed the extensive support she received from colleagues in her previous working environment.

Her cash-flow problems also forced her to discontinue paying for her son's full-time undergraduate studies and Leon had to enrol on a part-time basis. Marlene told me that she felt guilty for letting her son down. Matters were made worse by Leon's constant recriminations and complaints about her abovementioned decision. Marlene and Leon had regular quarrels over money. Their disagreements led to feelings of guilt that dated back to her marriage and her children's exposure to violence. At such times Leon often blamed her for staying in an abusive relationship with her first husband.

As another activating stressor, Karin relapsed into mania shortly after psychotherapy had commenced.

3.5.2.3 Maintaining factors

Marlene used an array of coping strategies to deal with her parental stress. Many of her stressors were related to Karin's aggression and disorganised behaviour during episodes of mania.

Marlene told me that she made regular use of positive reappraisal to seek religious meaning behind caregiving adversity and stressful life events. She also visited her siblings and other relatives for advice, guidance and support. She was especially close to one of her cousins, a retired nurse. Her second husband and other family members supervised Karin when Marlene was at work.

Importantly, Marlene's parental stress and dysthymia were perpetuated by the conflict that she experienced with Leon. Marlene's reaction to Leon's accusations vacillated between angry confrontations and appeasing behaviours. For example, during conflict she sometimes kept quiet while she gave Leon money for petrol or

other necessities. She also escaped from conflict by withdrawing to her room to watch a DVD.

3.5.3 Narratives of psychotherapy sessions

Session one

The first session was used to obtain applicable background information about Marlene's presenting problems. She attributed high levels of parental stress to interpersonal conflict with Leon, although she also had disagreements with Karin. Subjective symptom checks established a baseline of 80 for parental stress and 100 for guilt and self-blame. A BDI-II score of 16 confirmed moderate depressive symptoms. Even though Marlene often confronted Leon during conflict, she identified non-assertiveness towards him as one of her main problems. Non-assertiveness did emerge when she appeased him in the manner that I described in the previous section. Marlene gave a maximum baseline rating for non-assertiveness.

Marlene also stated that she became more irritable when her children were in conflict with each other. She blamed her son for these episodes by arguing that he should exert more self-control, because unlike Karin, he was an abled-bodied person.

As mentioned earlier, Marlene's conflict with Leon often revolved around money. She believed that he was manipulating her through his accusations in order to obtain money from her. Her feelings of guilt about past events in her first marriage were reinforced by his accusations:

Marlene: . . . of things is that, uhm... maybe (inaudible segment) of the guilt feeling.

OC: Mm?

Marlene: Guilt feeling because of, uhm: *why didn't I divorce immediately or... you know, that may be an issue!*

OC: [cross talk] Mm. Mm.

Marlene: Uhm, why . . . why . . . why?

While she often had strong reservations against his requests, Marlene would often give him money during or after arguments. This often left her with feelings of anger and resentment towards her son.

She disclosed that her eldest son saw some of the physical abuse that took place in her first marriage. Based on his heated expostulations and threats during conflict, Marlene was worried and fearful that her son would also eventually become abusive.

The following therapeutic goals were formulated:

- To reduce intense feelings of guilt and beliefs of self-blame.
- To significantly reduce the parental stress that she experienced with both children.

Session two

Marlene arrived early for the session and smoked a cigarette on the porch in front of my office. When I walked out to greet her, I immediately observed that she was not doing well: her affect was blunted and when she looked up she spoke to me in a slow and muted tone of voice

Once she was inside my office, Marlene described a negative experience that had occurred at work a week ago. She witnessed how one of her colleagues verbally

threatened a doctor following a disagreement. They reportedly had to physically restrain the person after she became aggressive. This happened in full view of the patients in the ward. Parental stress was rated at 70. She rated guilt and non-assertiveness towards Leon at 100.

We put the incident at work on the agenda. She was instructed by her supervisor to write and then re-write a statement of her observations, because her supervisor was not satisfied with the first attempt. Marlene told me that she was manipulated and bullied. The hospital management insisted that she attended the disciplinary hearing of her colleague. The person was summarily dismissed for unprofessional conduct.

I decided to follow supportive strategies and contain Marlene during the first part of the session. In a tearful and incoherent manner, Marlene stated that she felt guilty and responsible for her colleague's dismissal. She locked herself up in her room and spent the weekend reading fictional novels. She also considered the possibility of taking sick leave. I conceptualised these coping strategies as representing distraction (reading) and escape-avoidance (pondering whether to take sick leave to avoid work-related stress). On a thematic level, I conceptualised Marlene's self-blame as part of a broader belief system: *I am to blame*. The event also highlighted her problems with non-assertiveness.

We used guided discovery to explore her negative automatic beliefs that led to feelings of guilt across different relationships in her life. I also used the incident as an opportunity to socialise her to the CBT model.

I found the overgeneralisation of self-blame in this context significant: Marlene felt *entirely* responsible for her colleague's dismissal:

OC: Marlene, your automatic thought was: *It's all my fault*. You know, we tend to believe ourselves!

Marlene: [cross talk] It is all my fault because I was there!

OC: But is it *all* your fault? If I ask you to draw me a pie chart . . . I ask you whose fault is it? Please draw me how much you are to blame?

Marlene: I said it's *all* my fault, so that means I am . . . (inaudible segment)

I actively disputed some of her beliefs. Marlene reflected on the fact that there were 12 other people who had witnessed the event. Moreover, the medical doctor who laid the grievance against the other nurse also wrote a statement. Some of the patients were present; and a colleague recorded the incident on her mobile phone. With so many people involved, the hearing was based on more than just Marlene's account of events. We also discussed her supervisor's persuasive directive to alter her statement and I asked Marlene what one of her cousins, a registered nurse who Marlene holds in high esteem, would have done if she was placed in a similar situation. Her answer resonated with my provisional conceptualisation of many of Marlene's life challenges:

Marlene: I am not to blame, but I'm blaming myself.

I picked up on cognitive dissonance: there was a growing realisation that she could not possibly blame herself for *everything*. At a minimum, empirical evidence pointed to the role of other persons as co-contributors to the conflict and adversity she had experienced in her life.

Session three

Marlene's subjective symptom checks continued to measure elevated levels of parental stress (80) and feelings of guilt (70). However, she rated herself as becoming more assertive towards her husband and children, which she now ranked at 60.

When we covered bridging from the previous session, Marlene told me that Karin was becoming increasingly talkative, irritable, disorganised and energised. She was annoyed with Leon and Karin's constant bickering; and she sometimes also became involved in their conflict:

Marlene: He will just leave the house, because when you're not here at weekends; you're not here sometimes, you know, this . . . *"Because you (Leon) and Karin; me and Karin will argue, but between you two, I can't handle it!"* Then he will put the blame on Karin! *"You see what you're doing now?"* You know?

Marlene again stated that most of her conflict with Leon revolved around his requests to get money from her. We put the issue on the agenda and guided discovery was used to elicit Marlene's negative automatic beliefs and subsequent feelings.

She recalled a recent event when she received a phone call from Leon while she was sitting in the train. He first wanted to know if he could pick her up with his girlfriend's car, after which he asked her for money. Marlene struggled to identify her automatic beliefs and I provided her with examples of events, negative automatic

thoughts, emotions and behaviours. With assistance, Marlene was eventually able to identify the following automatic beliefs that occurred whilst she talking to Leon:

He knows I don't have money but he will ask anyway.

I'm worthless.

I am getting sick and tired of him asking for money; he should start working!

It makes me sad when I can't give him money because we can't get closure.

Why can't we have a normal mother-son relationship?

She was readily able to identify feelings of guilt, resentment, anger and sadness, especially if she gave him money following conflict. At other times she refused, but that tended to perpetuate her feelings of guilt. She also believed that her son's unwillingness to seek employment was an indication of his attitude that considered manual labour as being below his station in life. She thought that Leon was irresponsible with the money she gave him and unthankful towards her for keeping them financially afloat.

Session four

Marlene ranked parental stress, guilt/self-blame and non-assertiveness at 50. She described three episodes of assertiveness towards Leon and her extended family: First, she confronted her sister's son by informing him that he was no longer allowed to drink alcohol at their home during weekends. Second, she refused to accompany her sister to visit one of her brothers. She told me that she would have accompanied her sister in the past even if she did not want to go. Last, Marlene refused to give Leon petrol money:

Marlene: I think very different about him, because uhm . . . when I mean . . . when was (it) again? On Saturday, yes! Saturday, he asked me again for petrol money. But he went go (fishing?) with my cousin. So I told him: *“I’m fed up that you ask me for petrol money all the time!”*

OC: Mm. Mm.

Marlene: *“I’m not driving around with the car; you’re not working for the petrol money; and you got a girlfriend . . . Lift up your a** and start do something!”*

OC: Were you able to say this to him in the past?

Marlene: Uhm . . . in the past it was more (of an) argument.

We put her conflictual relationship with Leon on the agenda for further discussion.

Marlene completed a three-columned Dysfunctional Thought Record. A recent argument with Leon at home was used as one of the events that were included in the exercise. Marlene identified the following negative automatic thoughts:

I try my best and still you think that’s my fault as a mother; that I’m not a great mother.

Why don’t you go? I try my best!

Why am I also acting out?

Why can’t we be a normal family?

Similar to previous events, Marlene identified emotions that included anger, annoyance, resentment, sadness and guilt. She also blamed herself for becoming angry during conflict situations. Her conflict with Leon reminded her in some ways of earlier traumatic experiences in her marriage:

Marlene: I just put myself on that stool: you're not gonna hurt me anymore!

OC: [cross talk] Mm. Mm. Mm.

Marlene: Like your father did!

OC: I think there's something important to mention: there's a link here, isn't there?

Marlene: There's a . . .

OC: There's a link coming from an abusive relationship . . .

Marlene: [cross talk] Ninety per cent link.

OC: Ja. And now that-that you're older, you know, that your . . . Leon is a grown-up . . . ?

Marlene: You see, he's also got . . . he also got an anger in him.

OC: Mm?

Marlene: Because of his father.

OC: Mm.

Marlene: Now, that is like a everyday thing . . . at home.

Although we had made some progress, I thought that more unpacking and exploration were needed:

Marlene: Why can't he see my-my things? In my mind? On a certain . . .

(inaudible segment) Uhm, why can't he change things; why can't things be

normal? Why can't Leon see what I went through to put me in a same position . . . the same position . . . as his father. Uhm . . . why?

Session five

Marlene missed her previous appointment but told me telephonically that she felt less stressed and somehow "*lighter*". When the re-scheduled appointment started her feedback seemed to confirm our earlier conversation:

Marlene: I can cope . . . Because uhm . . . the other day one of the doctors said: "*Uh, Marlene actually came into work and . . .*" This morning I woke up I said: "*Jo, why I'm feeling just so . . . relieved!*" You know? Uhm singing down when I walked to work; and I came back, open the doors, into the wards. But why I feel so light? You know?

OC: Feeling lighter?

Marlene: Yes! I felt light. And one of the doctors I knew about the staff said: "*Hey, Marlene! I look at that - there's is something wrong! There's something funny!*" I said: "*I don't know myself, because I'm feeling so light!*" And the doctor came also said the same thing: "*Oh, just (inaudible segment) . . .*" So uhm . . . I . . . I'm better. I can't really express it.

Her symptom checks for parental stress, guilt and non-assertiveness were down to between 20 and 30. PSI-SF scores noted significant reductions in parental stress while PSOC scores suggested that her locus of control became more internalised. Marlene also measured higher on scales that measured parental satisfaction. BDI-II scores measured in the minimal range of depression.

Marlene told me that she visited her eldest brother to disclose details regarding her abusive marriage. According to her, she had never revealed so much information to him before, and the experience left her with a sense of relief.

We continued to explore some of the beliefs that were activated by her conflict with Leon. In this session, Marlene openly discussed her beliefs about being "a bad mother". We sought evidence in favour and against the belief of being a bad mother. Marlene became teary and emotional when she described some of the harsh parental practices that she had displayed towards Leon when he was a toddler:

Marlene: (sighs) First, number one, uhm . . . (pause) I punish him a lot. I fight with (him) a lot. I hit him a lot.

OC: Mm-hm?

Marlene: There was nearly every second and once when I hit him and I really hit him hard! Cause I could have gone for abuse. You know? Child abuse. So that's number one.

Marlene considered these practices as evidence in favour of her beliefs that she was a bad mother. Without minimising the perceived impact of the negative parental practices that she used to display towards Leon, we subsequently agreed that she was generally loving, protective and caring towards both her children.

We also sought plausible alternative explanations to account for the reasons why Marlene resorted to physical punishment and harsh parental practices towards a young Leon. Marlene agreed she was under enormous strain because of the ongoing intimate partner violence that she experienced at the time. Perhaps she was not a bad mother, but one who was challenged by extreme social

circumstances. She told me that she was tired of Leon's accusations about earlier events:

Excerpt:

You know, but . . . you know, cause that . . . that's why I thought I'll really work on that! No more. I was always a good mother; it doesn't matter what you (Leon) are saying now to me, and still I'm trying to do with his dad as well. He's a bad father – yes! He was totally! But if you can do change, the whole world can change!

Excerpt:

Marlene: So on Saturday he wanted to speak to me. Yes. So I said to him:
"I don't want to speak to you, Leon! Because you always go back! Is every time you must go back, back! I never see you going forward!"

Not for the first time, I noted that her ex-husband continued to visit their home.

Given Marlene's history and the severity of abuse, I thought at the time that it must have been difficult for Marlene to negotiate both her ex-husband's visits and Leon's persistent accusations about the past. Yet Marlene assured me that she processed the traumatic incidents that had occurred decades ago.

If we had the opportunity to pursue longer term therapy, I would have gently inquired and explored her contemporary relationship with her ex-husband and the impact of his visits. On a conceptual level, my sense was that their continued contact signified possible difficulties regarding boundaries, assertiveness and unequal power dynamics. Marlene described her second marriage in very positive terms, but I

believe that the impact of his substance dependence and alcohol abuse were possibly not fully disclosed.

While the session was productive and meaningful, I had to be more directive than I would have preferred to be. It was also difficult to maintain CBT structure. Not for the first time, Marlene became less coherent, and her verbal fluency was noticeably impaired. She often interjected and the session became rather stilted at times. I noted continued perseveration and Marlene struggled to switch between different topics.

I was aware that Marlene had suffered a minor stroke two years ago. After the session was completed I reflected on my observations that Marlene may have shown signs of mild neurological impairment at different intervals of therapy. I was again reminded that Marlene was facing serious health challenges that could have an impact on her psychological well-being and resilience.

Session six

Marlene missed two sessions despite her reassurance that she was motivated to continue psychotherapy sessions. I was familiar with the unpredictability of local train schedules and appreciated the time and effort it took Marlene to get to the clinic on days when she was not working.

Marlene made an appointment with psychiatry to treat her daughter's mania. While smoking in the courtyard in front of the Out-Patient Department, Marlene told me that Karin was now sleeping less than two hours per night. Karin was also becoming increasingly irritable and aggressive when requests were not met.

She told me that Karin spent each night packing and unpacking cupboards and often left most of the content outside. The commotion prevented Marlene from obtaining a good night's rest. Unlike her behaviour at baseline, Karin required constant supervision when psychiatrically ill.

Marlene's parental stress increased slightly as a result of Karin's behaviour. She gave ratings of 50 for parental stress and ranked her feelings of guilt at 40. She also ranked non-assertiveness at 40 (higher scores will imply a higher degree of non-assertiveness towards her family).

Although her subjective symptom checks were higher than the ratings she gave in the previous sessions, considerable progress had been made from her baseline measurements of 100 (parental stress), 90 (guilt) and 80 (assertiveness).

We used most of the session to discuss her management of Karin's behaviour and psychiatric illness. She lowered her care demands if Karin's arousal levels escalated and used extinction with low expressed emotion to manage Karin's manic behaviour. Marlene tried to make sure that her family employed the same strategies.

Her underlying philosophy was that she should take one day at a time because Karin will eventually get better again. Most of the session was used to validate and commend her for following sound caregiving practices. Her management of Karin's behaviour was based on her knowledge as a professional nurse with experience in the intellectual disability field.

Whilst talking about Karin's psychiatric illness, Marlene told me about her stressful encounters with the public mental health services. She described past incidents during which they had to wait for hours at the district hospital's ER. Marlene thought

that the attending doctors had a poor understanding of her child's needs. More specifically, Karin's dual diagnosis of ID and psychiatric problems made such long waiting times untenable. Furthermore, doctors often attributed Karin's behavioural problems to her existing diagnosis of ID even though it was evident that she was manic.

Her frustration was more geared towards the district health system. While she was generally satisfied with Karin's treatment at our clinic, she was frustrated by having to go through the district services each time her child got psychiatrically ill.

3.5.4 Interview after psychotherapy had been terminated

Marlene's positive feedback about psychotherapy confirmed clinical observations and psychometric assessment to suggest that she had benefited from the experience.

Consistent with her BDI-II and PSI-SF scores, Marlene described significant reductions in dysthymia and parental stress. She attributed these gains to her increased assertiveness towards Leon.

She also stated that her feelings of guilt towards her children were much less pronounced after we had discussed the earlier events regarding trauma and abuse in her marriage:

OC: If you think carefully about what we did in therapy: what did you find useful? What is it that you found useful? Just a bit more detail!

Marlene: The more thing . . . that happened to me . . . The more serious thing . . . I think . . . was serious about . . . never think it really bothered me, because I was just throw it around; or I blocked it . . .

OC: Ja?

Marlene: All the years I blocked a lot of things in my life. But the therapy helped me to bring it out . . . *My past.*

OC: Mm.

Marlene: That was a very important thing for me; it helped me. And my assertiveness.

3.5.5 Themes that emerged from thematic analysis

Theme	Excerpt
Parental stress and Karin's psychiatric illness with its accompanying behavioural difficulties.	<p>Marlene: She's actually starting again. High again.</p> <p>OC: Uhm, that was Wednesday?</p> <p>Marlene: And that's why I took her <i>mos</i> for the . . . the bloods, because they think she's toxic; she kept on falling. But it's still a high though. So my sister was there; she was talking and asking her to get her something. <i>"Why? Can't you stand up yourself?"</i> You know? <i>"You see this cup? I'll throw it you; to both of you."</i></p>
The use of CBT to reduce dysthymia and persistent feelings of sadness	<p>Marlene: I-I really don't . . . like before a month or two or a month ago, I still had it, but I didn't have it anymore. Like I use to have that feelings: crying, sit in the corner afterwards. And . . . because what's sometimes I'll read to three in the morning; (inaudible segment) or something like that. So that I don't do anymore.</p> <p>—</p> <p>Marlene: I feel lighter. I told you I think the last time?</p> <p>OC: You . . . Ja.</p> <p>Marlene: When I had that . . . not feeling sad to do something with my image. And I'm still doing make-up. I'm still . . . I didn't have time this morning . .</p>
Oscillating between angry confrontations and guilt-ridden, non-assertive appeasement: The impact of formative influences and early parental experiences on Marlene's conflictual relationship with Leon.	<p>OC: Okay. But the . . . but the acting out in front of him make you feel disappointed in yourself?</p> <p>Marlene: It does! Yes! It . . . I felt disappointed why . . . I said why am I doing this to him? You know?</p> <p>OC: Ja!</p> <p>Marlene: It's unnecessary going on, because sometimes I always feel I knew my husband to go on like this.</p>

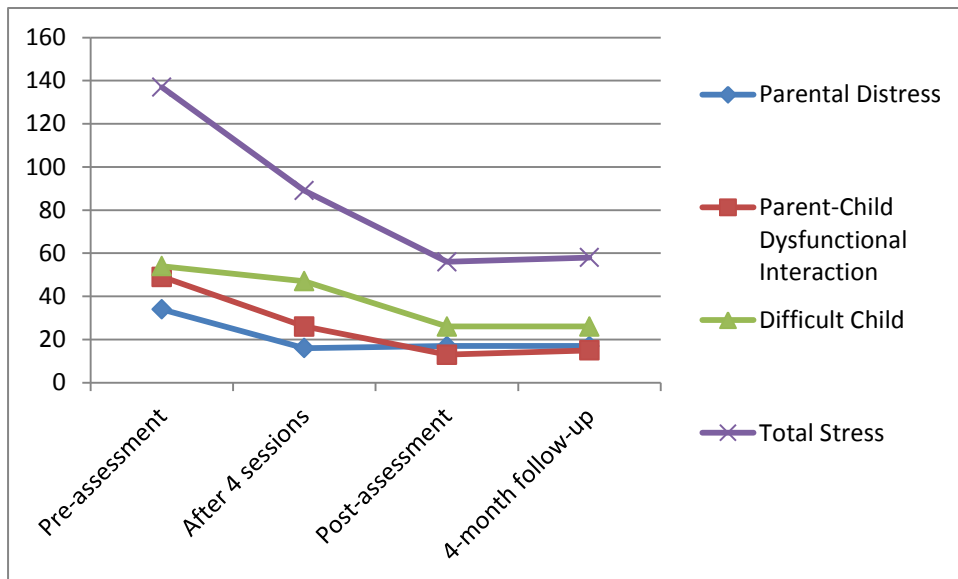
	<p>OC: [cross talk] Mm. Ja.</p> <p>Marlene: He wanted to take control here over me; everyone in the house; and it's an instinct . . . that's in a living creature, everything . . . that try to take over.</p> <p>Marlene: I try my best and still you think that's my faults as a mother; that I'm not a great mother.</p> <p>Marlene: I'm not saying ?(let's)? wiping it out (inaudible segment). But I don't feel that guilty if . . . like things that I said to Leon: <i>"Maybe it was because of me you do this blah-blah father's stuff!"</i> I don't feel guilty anymore. I don't feel guilty about his father. There's a time with his father, uhm, so I got us where I would've been: <i>"It's your legs; it's not my legs!"</i></p> <p>* Please refer to the last 2 excerpts of Session 4 and the 3 quotations of Session 5 for more examples.</p>
Conflict between Marlene and Leon as the result of financial strain	<p>Marlene: Cause why did he phone me? Cause of money! He knows mos! (But he knows!) I haven't got money or uhm . . . out of the way to spend!</p> <p>Marlene: Because I'm getting sick and tired of him going on about money! And it's . . . it's not working.</p>
Coping by escape-avoidance and distancing herself from conflict	<p>Marlene: (inaudible segment) incident on Thursday, so I was here on Friday so . . . when I left here, uhm, I just switched everything off.</p> <p>OC: Mm.</p> <p>Marlene: You know? So uhm . . . then from here I went home; I took my book and just read there till I think, probably till five o'clock I was reading. (example of escape-avoidance)</p> <p>Marlene: If it's me and him and Karin,</p>

	<p>then I will go . . . or I'll say: "<i>But now I'm walking away now.</i>" (Example of distancing).</p>
<p>Dissatisfaction about formal health support services</p>	<p>Marlene: I'm not talking about . . . I'm talking about the doctors.</p> <p>OC: Ja. I'm with you.</p> <p>Marlene: Yeah. Meet me halfway. I mean, if they can go back and start six months; more than six months and not that I want Karin to be in hospital!</p> <p>OC: Mm.</p> <p>Marlene: Cause it's a change from at home and to be in hospital. And maybe they think I'm lying; it's not what Karin is.</p> <p>OC: Mm.</p> <p>Marlene: You know?</p> <p>OC: What I'm hearing from you, and I want us to maybe start with that, uhm, is that the doctors need to meet you halfway and maybe they didn't quite meet you halfway this time? Could you tell me more about it?</p> <p>Marlene: Uhm, as I said, if I think back six months ago when I signed a red ticket . . .</p> <p>OC: [cross talk] Mm. Ja.</p> <p>Marlene: From . . . from ** [district hospital's name]. I even phone for ** [person's name] to see her; so uhm, nothing happened . . . they still let her be on the same tablet. The only thing they call . . . they would said . . . they gonna treat her on a new tablet that's not here; they have to order the tablet.</p> <p>Marlene: Ja, no that is the doctor that said: "<i>You must put the child into an institution; she's a vegetable!</i>"</p>

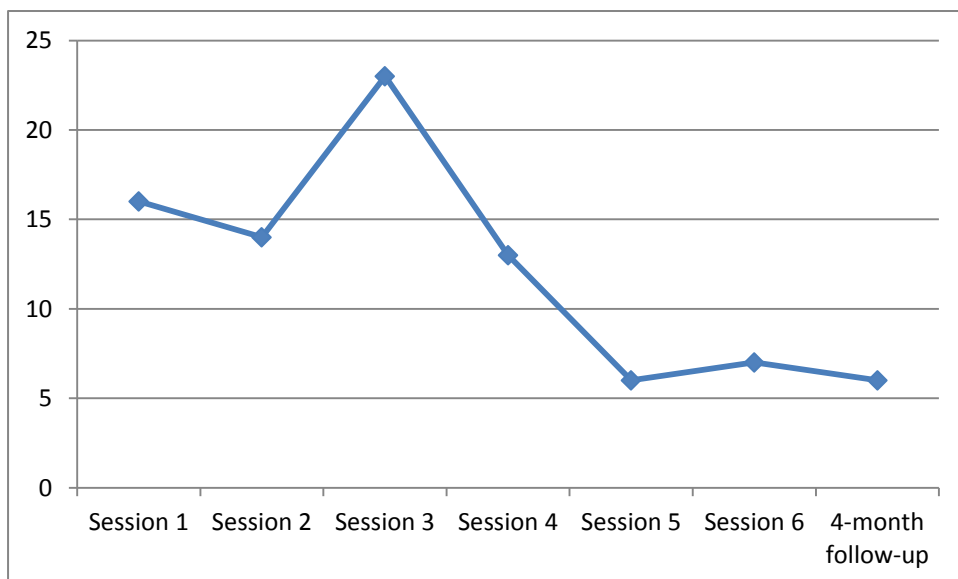
	<p>OC: Mm.</p> <p>Marlene: Right.</p> <p>OC: Nice.</p> <p>Marlene: So I said to her: <i>"I'm sorry, Doctor. My child is not gonna be a veg."</i></p>
<p>Sense of self as non-assertive and increased assertiveness later on in therapy</p>	<p>Marlene: Uhm . . . it never change, you know? By saying, the only thing as I said, assertiveness, yes, is still my weakest link.</p> <p>Marlene: That assertiveness . . . is a problem with me all the years. And this morning before I came here I went to my cousin's daughter, and I even said to her: <i>"You know, ** [person's name], I feel so good because, uhm . . . there's two things happened this weekend, and I was assertive enough. I could've said no!"</i></p>
<p>Example of cognitive variables (transversal across different themes that were identified)</p> <p><i>I am a bad and worthless mother</i></p> <p><i>I am strong but also vulnerable</i></p>	<p>Marlene: I feel, uhm... (pause) (sighs) There is times, uhm . . . I don't feel worthless as a mother, but I think sometimes with him...</p> <p>OC: Mm?</p> <p>Marlene: I'm worthless. Uhm...</p> <p>Marlene: . . . bomb everything up. But I don't . . . past I don't know, uhm, that I- I'm . . . when she said I'm strong, you know, then I said like: <i>"Yes, I am strong, but a strong person can also, uh, can down it . . . so don't think that I'm always strong."</i></p>

3.5.6 Psychometric test results

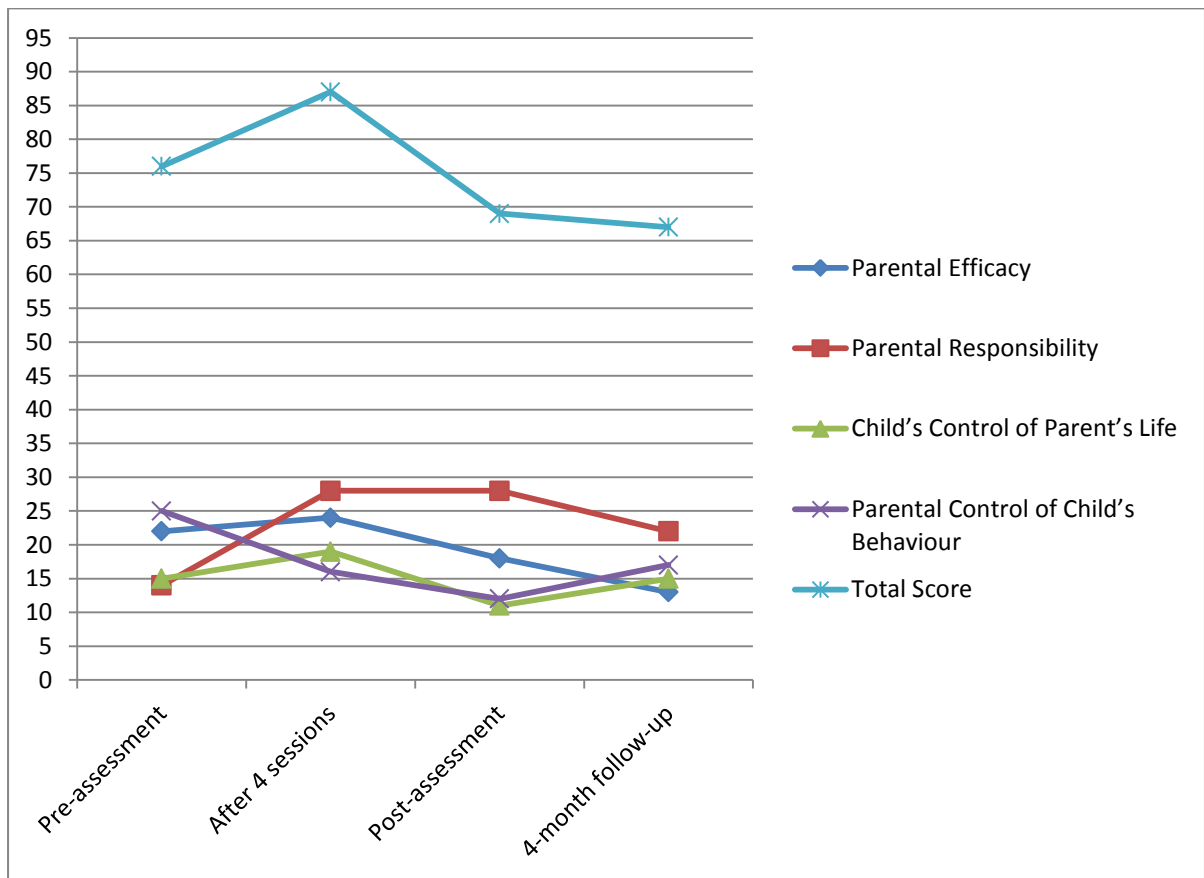
The Parental Stress Index: Short-Form (PSI-SF)



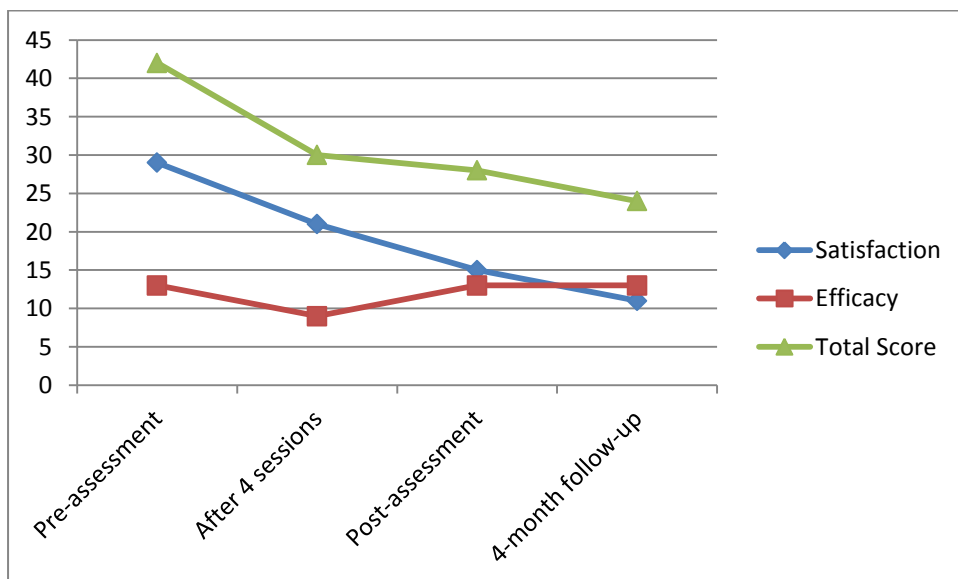
The Beck Depression Inventory II



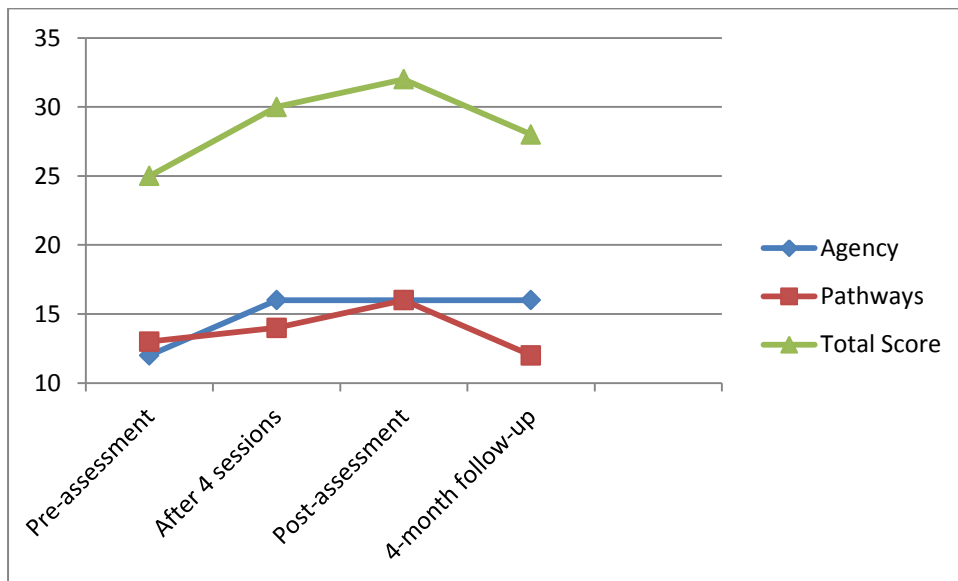
The Parental Locus of Control Scale



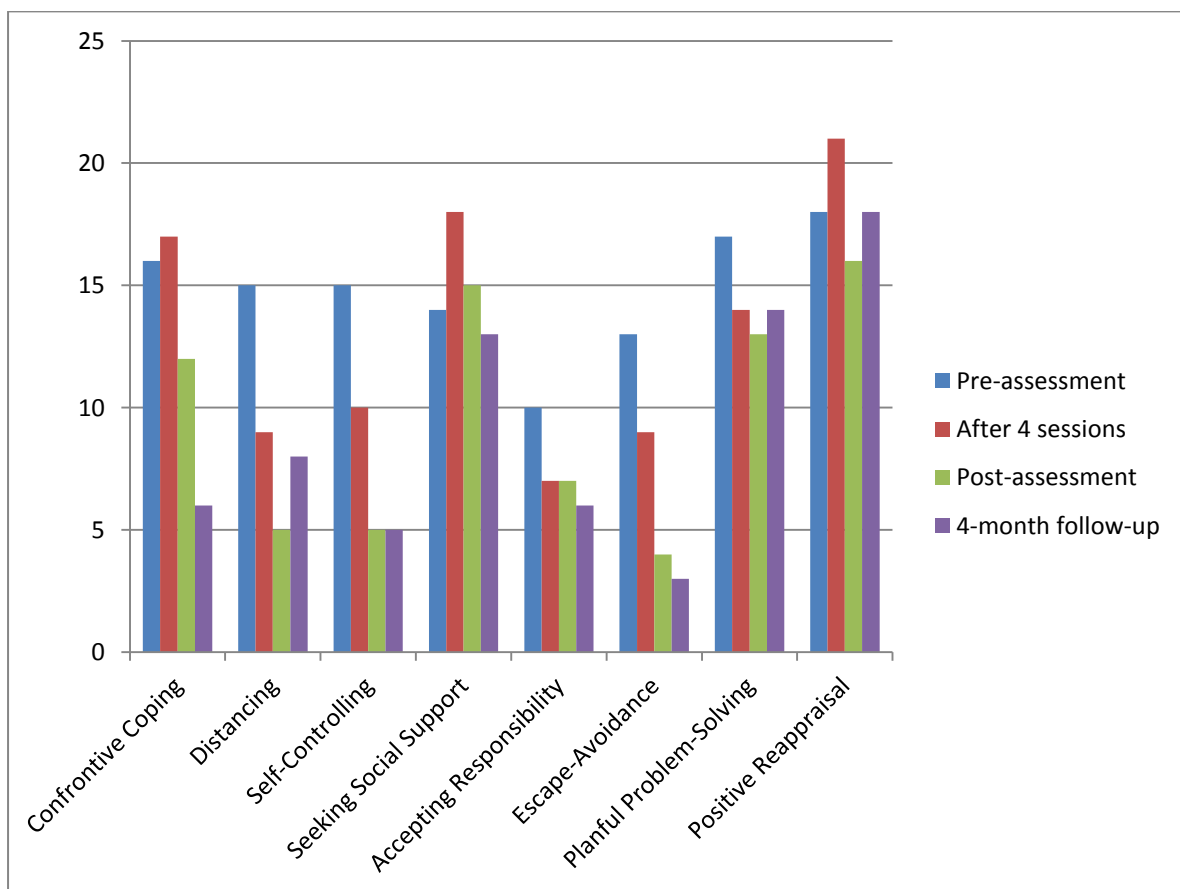
The Parenting Sense of Competence Scale



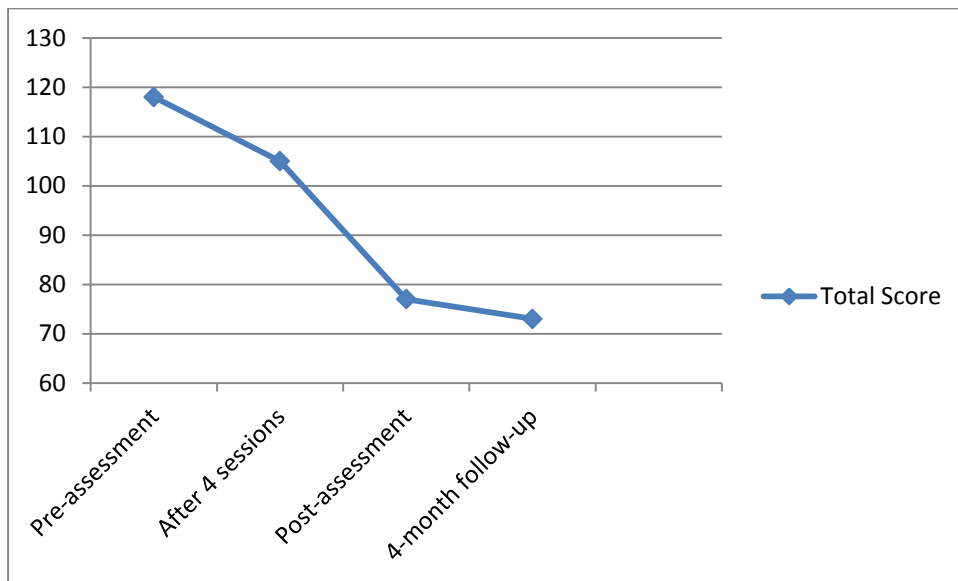
The Hope Scale



Ways of Coping Questionnaire: The Eight Ways of Coping



Ways of Coping Questionnaire: Total Score



3.5.7 Discussion

3.5.7.1 The use of CBT contributed to enhanced assertiveness as well as reductions in parental stress, guilt and self-blame

The psychometric results are presented in previous sections. The results underscored clinical observation and the feedback that Marlene provided: First, reductions in parental stress and symptoms of depression were maintained at follow-up assessment. She also shifted from a predominantly external locus of control towards a more internal locus of control and her parental satisfaction increased.

Marlene's disclosure of traumatic abuse to her brother might be responsible for some of the gains that were reported. Her discussion with her brother also signified a move away from self-imposed censorship towards the use of family support.

However, I would like to suggest that psychotherapy facilitated some of the positive changes which Marlene reported for the following reasons:

First, Marlene told me during the interview before the onset of psychotherapy that her parental stress and depressive symptoms had persisted over an extended period of time. It is therefore less probable that Marlene would have experienced a spontaneous improvement of symptoms concurrent with therapy.

Second, her conversation with her brother and disclosure of traumatic events in her marriage could also be seen as an extension of the therapeutic process. She approached her brother shortly after we had completed the fourth session. We covered aspects of her abusive marriage and her feelings of shame, embarrassment and guilt during the session.

Lastly, whilst in therapy, Marlene effectively changed her behaviour to deal with parental stress, anger, annoyance and guilt. She started to refuse giving her son money for unaffordable luxuries and expenses. Marlene also lowered her verbosity during conflict. She told Leon to stop blaming her and urged him to seek employment. As described in the narratives, Marlene also started to modify some of her beliefs about being a bad mother.

3.5.7.2 The impact of parental stress that was not caused by the child who had disability

It is interesting to note that despite the fact that our focus was on her relationship with Leon, Marlene also reported lower levels of stress in her relationship with Karin. Marlene was asked to complete PSI-SF forms based on her caregiving experiences with her daughter. Her baseline scores on the PSI-SF were above the 95th percentile even though she repeatedly mentioned that most of her parental stress was caused by Leon.

The relationship between parental stress and other life events was discussed in the literature review. Abidin (1995) acknowledged that parental stress may be perpetuated by any life event that negatively affects the capacity of parents to provide loving and responsive caregiving to their children. Accordingly, Marlene's parental stress was caused by more than just her daughter's behavioural difficulties and psychiatric illness. Her capability to render care was negatively influenced by many other variables such as her conflict with Leon, her occupational stress and financial strain.

I believe that Marlene's parental stress was lowered after she started to implement different coping strategies to deal with family conflict. The results of the Ways of Coping Questionnaire are presented in the previous section. As with other psychometric measurements, Marlene completed the WAYS before the onset of intervention, after four sessions, at post-assessment and 4-month follow-up.

Towards the end of therapy, Marlene started to make significantly less use of *escape-avoidance* when coping with parental challenges involving either Karin or Leon. As mentioned in other case studies, research has found an association between the use of escape-avoidance/mental disengagement and depressive symptoms among mothers of children who have ID (Glidden et al., 2006; Paster et al., 2009; Woodman & Hauser-Cram, 2013).

Marlene told me during the post-assessment interview that her relationship with both children had improved. Whilst her feelings of guilt and perceptions of being a bad mother were often linked to Leon, Marlene also developed more general beliefs of her parenting involving both children.

For example, Karin's premature birth was the result of IPV. The internalisation of guilt and self-blame at not being able to protect Karin against her husband resonated with similar beliefs she held about Leon's exposure to abuse. More specifically, he had witnessed some of the most harrowing episodes of physical violence when he was a toddler.

3.6 The Sixth and Last Case Study: Sarah

3.6.1 Introduction

At the time of therapy, Sarah was a fifty-nine-year-old retired woman. Her son, Ethan, was nineteen years old. He was diagnosed with Fragile X, moderate ID and autism. Ethan was referred to one of the other psychologists in our service because of his aggression. He presented with autism-related problem behaviour and found it difficult to adapt to changes in his routine.

Ethan's aggression often stemmed from situations when his requests for food and snacks were not met. Having just completed 13 years at a school for children who have autism, Ethan did not have structured activities at home and spent most of the time watching television or following his mother around the house.

Ethan's psychologist reported that Sarah was depressed with high levels of parental stress. Sarah was subsequently invited to participate in the study.

Her husband passed away more than ten years ago and five children were born from their marriage. At the time of therapy her children were aged between nineteen and forty-four. Sarah got involved in an intimate relationship with her then future-husband when she was fifteen and they married when she was twenty-six. She described a long and happy marriage, but noted that her family was against their relationship because her husband was thirty-two years older than she was.

Sarah had worked in the textile industry for over thirty years and retired about seven months before she started attending therapy. She lived with Ethan and her twenty-two-year-old daughter. She had received a state pension since retirement.

She was on treatment for hypertension and cholesterol. Sarah was also diagnosed with depression. At the time of therapy she had been using fluoxetine for two and a half years. Genetic testing confirmed that Sarah was a carrier of the FMR1 premutation.

3.6.2 Case formulation

3.6.2.1 Predisposing factors

Sarah was raised by her mother's aunt and recalled happy childhood memories. Moreover, she felt connected to everyone in her closely-knitted neighbourhood. After her husband passed away in 2001, Sarah left most of Ethan's caregiving responsibilities to her ageing mother. Despite receiving considerable support from the church, Sarah made repeated references to her lack of family support and relative isolation from her children. As I will describe in the narratives, Sarah also presented with mild traits of autism with associated social skills deficits and impaired social communication. Features of autism were conceptually linked with some of her caregiving challenges and high levels of parental stress.

3.6.2.2 Precipitating factors

Sarah's retirement and Ethan's graduation from school meant that they were spending most of their time together. Ethan did not display marked behavioural problems whilst still attending school, although behavioural difficulties were noted at home.

Sarah told me that her savings were quickly being eroded by family members who borrowed money without giving it back. Ethan's behavioural difficulties had also become more pronounced in terms of frequency and severity since he had left school. Sarah also felt confused, hurt and angry by the borrowing practices of her

family and their perceived lack of willingness to assist her with Ethan's care and the management of his behaviour.

3.6.2.3 Maintaining factors

At the onset of therapy Sarah was clinically depressed, with high levels of parenting stress. Much of her psychological distress was maintained by the same underlying perpetuating factors: Sarah's social comprehension and social skills with reference to reciprocal conversation and the modulation of overtures showed significant impairment. Although Sarah was not formally assessed by means of standardised psychometric instruments such as the Autism Diagnostic Observation Schedule, Second Edition (ADOS-II) (Lord et al., 2012), a multitude of subtle signs of autism suggested milder manifestations of traits in a person who was functioning independently.

To avoid unnecessary repetition of this theme, more information about the manifestation and presentation of social impairment will be covered in the narratives of sessions.

3.6.3 Narratives of psychotherapy sessions

Session one

The first session was used to obtain applicable background information and assess Sarah's amenability to psychotherapy. Subtle signs of semantic and pragmatic impairment in Sarah's use of language were observed throughout the session:

First, Sarah spoke in a high-pitched, amplified, monotonous and uninflected tone of voice that showed little deviation when she described different emotions such as anger and sadness.

Second, she made little use of gestures during conversation; she mostly sat rigidly on the sofa with both hands extended on her knees. Sarah tended to answer "yes" or "no" without displaying accompanying conventional gestures (Lord et al., 2012). When describing Ethan's behaviour and other events, Sarah seldom made use of descriptive gestures. Likewise, emphatic gestures that provide emphasis to verbal communication were almost absent. For example, I counted only three such gestures during the first session. Besides an idiosyncratic expression by which Sarah would raise her eyebrows whilst simultaneously pouting, she had displayed limited facial expressions.

Third, Sarah maintained minimal eye contact, and mostly averted her gaze.

Fourth, at times the detail and inclusive nature of Sarah's responses to questions made it difficult to distinguish essential content; and she displayed some difficulty in separating relevant from irrelevant aspects of events. Furthermore, Sarah often perseverated on topics that were related to her finances. She went into minute detail without checking whether I was following her.

Last, Sarah's social communication and overtures were of low quality and quantity when considering her developmental level of ability. Social overtures can be defined as efforts to instigate *purposeful* communication, e.g., checking whether somebody is following your line of reasoning. It also includes eye contact and other non-verbal behaviours to elicit a response from the other person (Lord et al., 2012).

While Sarah offered information and answered questions, the content of responses was often presented with little exchange of conversation; she also seldom asked for information to build on statements during discussion. Thematic analysis confirmed my clinical observations to suggest that Sarah was less inclined to provide full-

sentence answers to topics that were not introduced by her. She provided little or no indication whether she was agreeing or disagreeing. Interjections such as “*mm*” and “*mm-mm*” were all but absent in her speech.

She would at times repeat the word “*okay*” when I was raising some points for discussion; and these words were uttered with very little inflection; and in an almost mechanical way.

It is possible that her limited eye contact and lack of reciprocity might have been caused by social anxiety or shyness. She did not come across as shy. Sarah had no tremor in her voice or other verbal or non-verbal indications of social anxiety. I also remember walking past her in the waiting room while she was having an animated conversation with other parents. She subsequently told me she had met them that day for the first time. She participated in church-activities that included people she did not know well, and there were no indications of social avoidance even when Ethan acted out in front of strangers in her community.

She reported that her husband “*did everything for me*”. She complained about her children’s lack of support in managing Ethan’s care:

Sarah: . . . and I’ve built up a nest egg for me. Now . . . I feel I’m in a position to help my children . . .

OC [interjection]: Hm.

Sarah: . . . but they’re not actually there for me.

Notwithstanding her complaints about inadequate family support, Sarah attributed her depressive symptoms and parental stress solely to Ethan’s behavioural difficulties.

Her persistent difficulties in social interaction and communication were incorporated into the case conceptualisation. I believe that Sarah's amenability to psychotherapy was lowered and it was difficult to establish a strong therapeutic alliance (e.g., Wright et al., 2006). More information was required about her relationship problems with especially her children; and assessment also had to consider her existing coping strategies and resources.

Session two

In the first session we had run out of time to cover the rationale of symptom checks and obtain baseline measurements for parental stress. In the second session Sarah gave maximum ratings for parental stress. Her BDI-scores on baseline suggested severe depression but the BDI-II scores of the second session measured minimal depression.

My case conceptualisation considered Sarah's lending practices as potential stressors and I therefore asked her to measure her assertiveness towards family members, especially when they asked her for money. Being a carrier of the FMR 1 premutation, Sarah also told me that she felt guilty and responsible for Ethan's diagnosis of Fragile X. We therefore measured her subjective rating of feelings of guilt, which she rated at 70 during the second session.

Before we were able to set the agenda, Sarah started to elaborate on Ethan's behaviour and her daily efforts to manage them. She told me that Ethan broke a glass after she had refused to give him a fizzy drink. Other incidents of physical aggression and destructive behaviour were also reported. In an angry tone of voice, Sarah repeatedly ascribed Ethan's behaviour as efforts of seeking attention to *"get his way"*. His acting out behaviour often followed denied requests for snacks such

as cold drinks, candy and chocolate. Sarah was worried and stressed about the money she had to spend on non-essential food items and accused Ethan of overindulgence. When asked about her management of Ethan's demanding behaviour regarding food, Sarah responded that she usually met his requests to prevent his behaviour from escalating.

Sarah provided long and detailed descriptions of the food items that Ethan consumed. For example, she listed ten consumables that Ethan had eaten during the course of the previous week. She also tended to provide the quantity of the items that were consumed. Efforts to structure the session were mostly met by a curt "*okay*", after which Sarah continued her detailed listing of Ethan's eating habits.

Besides her stress about Ethan's behavioural difficulties, Sarah continued to worry that she might not get her money back from family members. Consistent with her lists about Ethan's food items, Sarah listed people and the amount of money they owed her:

OC: I'm fishing out here because I want to get a sense of how bad it is, Sarah?

Sarah: [middle son's name], when he stayed with me . . .

OC: Mm-hm?

Sarah: . . . he didn't pay . . . he stopped working, and then, when he got his money, he gave me half the mon . . . not even half the money (plastic packet rustling). [Middle son's name] owes me more than R10 000.

OC: Mm?

Sarah: [Eldest daughter's name] owes me 3 000, [brother's name] owes me 3 000, that's my brother. But he's okay, he's, he said he's gonna pay me the end of the year, which I'm fine with. And his son, I offered to help him because he lost his work, and I said I'll cover his debt so that it doesn't gain interest, and, uhm . . . and he can pay me whenever he's ready. So that's another 3 000. Between the three Rs there's 9 000. [Middle son's name] owes me more than 10 000, which I've written off. And then [middle son's girlfriend's name] owes me money, that's not a thousand, and then they asked me to buy for [grandson's name] . . . they gonna pay me 150 a month, which never materialised. That was almost another 1000. And then December . . . it was . . . November, [woman's name] asked me for 15 000 and I said to her: *"I don't have 15 000."*

OC: It's a lot of money!

Sarah: And then . . .

OC: [interjection] *Sjoe!* (My word!)

Sarah: . . . I gave them my card . . . and they used R12 000 from my card, which was all the money, even my wages that went in there. I gave them, and then Dec . . . not December . . . I think January . . . March, I closed my account by [bank's name]. There was 6 000, because that was my savings account, and because I stopped working . . . there was no savings going in there, so I closed that account. I gave the 3 000 to [man's name] and 3 000 to [man's name]. That was that money.

OC: But Sarah, we're talking already . . . about over R30 000!

Sarah: And then, I helped another girl at work last year, and I said to her: *"I'm in a position to help you, but just remember, next year . . ."* She promised also to pay me 500 a week. So, I said to her . . . because next year I'm going, I'm at home, and you know I'm not getting an income, so you need to see, to look after me. But she didn't. Sunday, Saturday she sent me a sms to say that . . . she's sorry, but she can only see me today. So I said: *"You're not very funny."* Because last week I had to use my son's money to pay my debts.

OC: Hm.

Sarah: Not actually my debts, my business, to cover my business. And, uhm . . . then, she came Sunday morning . . . And then I just said to her, uhm: *"If you've got a problem with money you must talk to me, then I won't bother you."* But it doesn't mean that they don't have to pay me.

OC: Hm. (clothes being ruffled)

Sarah: She owes me . . . four an' . . . four thousand . . . almost four and a half thousand rand.

OC: Hm-mm?

Sarah: That's . . . and then another lady owes me [business's name] money. And I sent her a sms to say I'm gonna give her over to the lawyers. And then she phoned . . . she sent me a please call me, and then, last week I've, I sent her another sms and I said they're giving her just one week . . .

OC: [interjection] Hm.

Sarah: To come with the money. That's over R1 000 . . . And that's besides the money that I've written off from the other people.

OC: Okay. So Sarah, we're talking about over 30 000, which is a lot of money.

Sarah: It is a lot of money.

OC: My question to you is, and again, we just, you know, we'll still talk about it in more detail, but my question to you is: if [middle son's name] comes to you, any of these guys come to you again, and they ask you for money, what will you do?

Sarah: I will give it to them!

OC: Mm?

Sarah: I will just, like . . . now, two weeks ago, my sister-in-law phoned me (clothes being ruffled, feet shuffling) . . . they owe me more than (page being turned) R2 000. And then they've got the audacity to ask me for another 2 000.

The repetition of words and phrases, e.g., "*and then*" is noticeable.

Lending represented a repetitive behaviour which informed a tentative conceptualisation of such behaviours as representing cognitive inflexibility and problems with generalisation. Sarah continued to lend money and expected relatives to pay her back despite evidence of persistent non-payment. Believing that her children are avoiding her because they felt guilty for not repaying her, Sarah was

also experiencing considerable distress about "*the money situation*" and her family's reported avoidance.

At a minimum, the emerging pattern of lending pointed to social difficulties in resolving her family's potential exploitative behaviour towards her. Even if Sarah held beliefs that she had to give family members money to buy their goodwill, her subsequent psychological distress and her family's avoidance highlighted considerable psychological distress about her lending practices.

In order to formulate therapeutic goals, I conceptually linked her non-assertiveness towards family members with difficulties in social comprehension, social skills deficits and possible cognitive perseveration and behavioural inflexibility. Based on these considerations, I had to be rather directive and yet sensitive to Sarah's style of interaction when we formulated the following therapeutic goals:

- To manage Ethan's behavioural difficulties more effectively and to be more in control when he acted out in an aggressive manner.
- To significantly reduce parental stress.
- To significantly reduce symptoms of depression.
- To become more assertive towards people who requested money without showing any intention of paying her back.
- To reduce her self-blame and feelings of guilt that she was responsible for Ethan's Fragile X by being a FMR1-carrier.

Session three

Symptom checks improved from previous sessions: parental stress came down from 100 to 60; she was more assertive (non-assertiveness came down from 70 to 50); and guilt and self-blame measured slightly lower (70 to 60). BDI-II scores measured in the minimal range of depression.

While bridging from the previous session, Sarah reported that an acquaintance approached her to borrow money. She took an assertive stance by refusing to lend the person money but felt guilty about this afterwards. However, she also felt relieved because she had limited financial resources. We briefly discussed the need to continue to be assertive towards family members and acquaintances by refusing to lend them money.

The management of Ethan's behavioural difficulties was placed on the agenda. Sarah attributed lower levels of parental stress to the relative absence of episodes of aggression and destructive behaviour during the course of the previous week.

Similar to the previous two sessions, open-ended questions to facilitate discussion were often met by a short, poorly-modulated affirmation – “*Ja!*” – after which Sarah changed the topic of conversation in order to pursue her own interests. She listed food items and discussions of what she prepared for Ethan. I was therefore more directive than in previous sessions by interrupting Sarah at times to focus on Ethan's behavioural difficulties and her management of same. Sarah also reported difficulty in completing the three-column Dysfunctional Thought Record. We used an episode of Ethan's aggressive acting out to identify salient beliefs as well as emotional and behavioural consequences.

She described recent episodes of physical aggression that were directed against her. Two of the three outbursts took place while they were shopping in town; the third event occurred while they were waiting for one of her other sons to pick them up for Christmas lunch with her family. By being insistent on remaining focused on Ethan's behaviour, Sarah was able to make links between the event, beliefs, emotions and behaviour:

- Event: Waiting for her son to pick them up to attend Christmas lunch; Ethan gets agitated and starts throwing stones.
- Automatic thoughts: What if he breaks a car's window? What if people expect me to pay for the damages? I don't have money. What if Ethan gets aggressive towards me? What if I get hurt?
- Emotions: Feeling scared, apprehensive, and angry.
- Physiological response: Developing a tremor.
- Behaviour: Giving Ethan food to distract him. Confronting Ethan by raising her voice and reprimanding him.

Sarah told me that she became angry at Ethan during these episodes. On all three occasions Ethan acted out after his requests for specific food items had been refused. The incidents also involved a change in routine. He was required to leave home and enter a public space or attend a family gathering. I believe that Ethan's behaviour could most likely be explained by his autism. As indicated by reports from the school he attended, Ethan benefitted from routine in a structured environment. Autism also implied that Ethan might have experienced some discomfort in large groups of people or during social events.

Towards the end of therapy, Sarah looked up in a rare moment of appropriate eye contact. She then told me that she frequently “*hits*” Ethan. With prompting she added that he usually retaliated immediately by acting aggressively towards her. We decided to explore this important issue in our next session.

Session four

While parental stress continued to measure at 60, Sarah reported improved assertiveness towards others (non-assertiveness = 20); her feelings of guilt also measured lower at 20; and BDI-II scores remained in the minimal range of depression.

Similar to previous sessions, Sarah provided long lists of food items. On six occasions Sarah interrupted me to continue with some of the discussion items that she introduced. Her speech was pedantic with various repetitions of phrases such as “*bad luck*”, “*it’s working for me*” and “*even if I have to say so myself*”.

It was therefore challenging to structure sessions in accordance with the recognised format of CBT sessions (e.g., Beck, 1995) with a set agenda. We continued to discuss the management of Ethan’s behavioural difficulties. Her beliefs about Ethan’s behaviour suggested rigid labelling and selective abstractions: Sarah stated that she had to allow Ethan to “*get his way*” in order to prevent episodes of deliberate aggression and acting out behaviour. She therefore anticipated his intentions based on previous incidents, thereby discarding evidence of episodes when Ethan did not act out when requests for food were not allowed.

She also did not consider the conflict between mother and son as potential setting events that led to Ethan’s acting out behaviour. Sarah became frustrated and angry

when Ethan displayed demanding behaviour. As described in the previous narrative, during such incidents she often reciprocated aggression by lashing out at him. At such times she did not give in to his requests for food and other items.

Her parental stress, worry and apprehension about her son's potential acting out behaviour and aggression were also prominent at times when she left Ethan in the care of her brother or other family members. At such times she "*sneaked out*" of the house without saying goodbye to her son. Following her brother's recent request to tell Ethan when she planned to leave him in their care, Sarah started to inform Ethan about her plans before she left her brother's house. Further exploration suggested that Ethan was sensitive to Sarah's non-verbal cues of worry and apprehension when she had to leave him without informing him about her intention. She stated she felt more relaxed since she had started telling Ethan that she had to leave him because of other appointments and activities.

I reinforced the importance of disclosing her plans to her son before she left him in the care of family members. Tentative links were made between Sarah's non-verbal signifiers of apprehension and worry, Ethan's sensitivity to her non-verbal cues, and the potential benefits of feeling more relaxed prior to these volatile situations: First, Ethan's behaviour may improve because his mother's non-verbal behaviour is more relaxed. Last, she is also more in control of the situation when she discloses her intentions to her son.

With the exception of her youngest daughter who was living with her, Sarah told me that her other children were avoiding her and seldom visited her. Sarah confirmed that she felt hurt by their behaviour and lack of support. She told me that her sons only made contact with her when they wanted to borrow money. She tended to

ignore text messages or phone calls. Sarah also told me that she often confronted them by asking them why they wanted nothing to do with her.

Session five

Subjective symptom checks remained at similar levels to the previous session and BDI-II scores continued to measure in the minimal range of depression.

The session was used to explore Sarah's beliefs regarding Ethan's behavioural problems and the underlying aetiology of his aggressive outbursts and acting out behaviour.

Sarah described some of Ethan's behavioural difficulties during the course of the previous week and repeatedly stated she was "*hitting*" her son in order to discipline him and stand up against him:

OC: Hm. Sarah, if I could just stop you there. I mean, I'm getting a sense of how difficult it is! But I want to know from you . . . uhm . . . let's take this morning's episode when he pulled your hair, was it this morning?

Sarah: No, was . . . Monday evening.

OC: Monday evening? Shall we go back? Let's say when he pulled your hair, what were you thinking about, what was going through your mind?

Sarah: (voices in the background) I just turned around to him and I hit him, and I said: "*Now why you pulling my hair?*"

OC: Hm?

Sarah: And then he just smiled at me. Like he's taunting me!

OC: I think he . . . it sounds like he's taunting you a bit. Okay . . .

Sarah [interjection]: Just to see how far I will go, but . . . I've come to the point if he pinches me, then I will pinch him back.

Sarah became angry when I suggested that we explore ways of managing her son's behaviour without resorting to strategies that may reinforce her son's aggression.

She made eye contact and told me: *"It is easy for OC to say!"*

Besides Sarah's reciprocation of her son's aggressive outbursts, she described aspects of parent-child interaction that raised questions about appropriate boundaries and an enmeshed relationship:

OC: Hm. Okay. Sarah, if I could ask you, I mean, it sounds like it's very difficult to deal with his behaviour, but I want us . . . what makes you feel that you don't have any control . . . in this situation? Why do you feel that there's absolutely no control? I'm asking. I want to understand . . .

Sarah [interjection]: Because he's . . . he's stronger than what I am, an' if he wants to do something to me, he will do it. He's like taunting me. Say, uhm . . . like this morning, for instance, when I was sitting (shuffling), I had to get finished (shuffling) so that he can sit on the toilet, because he was pulling me up.

OC: Ja?

Sarah: Like yesterday, I was sitting in the toilet, now . . . we've got this game that we play . . . he will take the toilet roll and he will throw it and I will throw it back to him. So I thought, when he was taking the toilet paper, he was gonna throw it, we were gonna play catch-catch. But then he took the toilet paper

and he threw it on the cupboard's roof (shuffling), and then . . . [woman's name] had to come up and give me the . . . bring me toilet paper, because he threw it there in the room.

OC: This is while you were on the toilet?

Sarah: Ja.

She also reported that Ethan was masturbating in bed and complained about the laundry and sheets she had to change. It was only after the session had been completed that I realised they shared a bed. Ethan was therefore masturbating with his mother lying next to him.

With considerable prompting, Sarah identified feelings of fear and anger when her son displayed aggression or acting out behaviour. An opposing and conflicting belief system emerged: On the one hand, Sarah pointed to the use of medication to calm her son down and described his behaviour as the result of what I conceptualised as neurobiological mechanisms; she described his behaviour in vague terms as being linked with his brain and autism. On the other hand, she also stated he was "taunting" her and acting out when he did not get his way.

Thematic analysis linked her feelings of anger with perceptions that her son was intentionally provoking her. She simultaneously worried about her physical well-being; and she had automatic images and thoughts of having a stroke whilst Ethan was aggressive towards her. Diagnosed with arthritis, Sarah was also worried and fearful about getting hurt.

Session six

Symptom checks were similar to the previous two sessions: parental stress at 50; guilt and self-blame at 20; and non-assertiveness at 10. BDI-II scores remained in the mild range of depression.

Sarah reported that Ethan's aggression had increased significantly in frequency and severity during the course of the last week. Apart from her existing coping strategies, i.e., alternating between lashing out at him, crying to make him stop, or giving in to demands regarding food, Sarah also disclosed a sense of helplessness about managing his behaviour:

Sarah: It's like . . . I dunno what his mind is telling him . . . I'm angry, at first it used to work, but now it's not working, me crying is not working anymore for him. Because he used to calm down when I start crying. But it's not working anymore.

As a homework exercise aimed at assisting with the planned implementation of behavioural management strategies to replace Sarah's current ways of coping with Ethan's behaviour, Sarah was asked to think about worst case scenarios when Ethan started to become aggressive. This was in part due to the identification of automatic beliefs that suggested catastrophic thinking prior and during behavioural outbursts.

On a conceptual level, my sense was that Ethan's behaviour could be more effectively managed by applying the basic tenets of differential reinforcement. I also believed that OT intervention would be able to assist with plans to decrease her son's boredom and provide structure to his day. I was hopeful that the successful

implementation of these longer term strategies would enhance Sarah's locus of control and lower her levels of parental stress.

Visual aids were used in this session to augment discussion; key concepts were also repeated to facilitate memory encoding and reduce some of the cognitive inflexibility that was previously observed through focussing on visually-presented material.

We were able to identify the following:

Event: Sarah standing in front of Ethan during episodes of her son's aggression.

Automatic thoughts: *What if he hurts me really badly? What if I get a stroke? What if I get a heart attack? What if I "snap" and hurt him really badly?*

Perceptions of helplessness, i.e., *there is nothing I can do to make him stop.*

Emotions: Fear, anxiety, apprehension and anger.

Behaviour: Giving in to Ethan's requests or lashing out at him.

Open-ended questions were asked to explore the consequences to Ethan and Sarah if she gave in to demands or lost her temper. Sarah agreed that both strategies were ineffective. She became emotional and stated that she knew no other way of managing his behaviour.

I tried to show how both coping strategies could maintain aggression. Sarah's feedback suggested beliefs that his behaviour would continue to be uncontrollable even if she should attempt other strategies.

Psychoeducation in the basic principles of the low arousal approach was provided, albeit with simplifications: the idea of crisis was covered, including Ethan's lower

receptivity to Sarah's parental input during crisis and the need to wait until he calmed down before attempting more assertive management strategies.

Cognitive strategies were again used to try and change her beliefs that Ethan's behaviour posed a severe and persistent risk to her physical health. Discussion elicited a significant point: if Ethan's behavioural difficulties evoked heightened maternal agitation, the decision to ignore such behaviours would not necessarily result in reduced distress. In fact, Sarah told me that she continued to feel resentful and agitated in situations where she had met Ethan's demands notwithstanding her reservations not to give in to his requests. If Sarah associated her agitation with an increased risk to her physical health, her efforts to reduce such risk would be rendered ineffective if her agitation and arousal persisted.

We agreed that Sarah would go for a medical check-up to see if her concerns were substantiated by a thorough medical examination.

Session seven

Sarah provided the following symptom-check ratings during the final session: parental stress = 40; non-assertiveness = 10; and guilt and self-blame about being responsible for her son's Fragile X = 0. BDI-II scores measured in the minimal range of depression.

As a homework assignment, Sarah was asked to think about possible ways of dealing with Ethan's behaviour in future; to think critically about possible solutions, no matter how improbable the implementation of some of the strategies might have appeared at face-value.

Sarah stated that placement for Ethan in a community-based residential setting appeared to be *"the only solution to my problem"*. While Ethan would most likely benefit from placement when considering his limited levels of stimulation at home, restricted social inclusivity and a generally low quality of life, I conceptually linked Sarah's response with a degree of cognitive inflexibility and rigidity which translated into dichotomous thinking.

With cognizance to her son's behavioural profile and the shortage of residential placement options, we allocated time to brainstorm different strategies of managing Ethan's behaviour. Part of this process entailed the identification of trigger points which activated feelings of fear and anger when Ethan started to act out. I also wanted to look at concrete cognitive and behavioural strategies such as decatastrophising, breathing exercises and thought stopping to reduce the distressing impact of maternal physiological arousal, apprehension and fear prior and during Ethan's behavioural outbursts.

During the brainstorming exercise, Sarah repeatedly stated that her only recourse was to seek placement for Ethan. Open-ended and more directive questioning did not amount to more than short phrases or abrupt replies. Sarah identified the possibility of *"locking Ethan up"*. In light of the lack of progress during the brainstorming exercise, we were unable to proceed with discussion about implementing some of the possible strategies that were mentioned in the previous paragraph.

Sarah did not change her parental practices to manage Ethan's behaviour. She cited an incident during the week when she lashed out at him with a plank. I again stated my concerns about her parental practices in this regard.

Sarah informed me after the session that she struggled to arrange transport to continue psychotherapy. I would have wanted to continue sessions, at least to a point where more tangible practical arrangements were in place concerning applications for Ethan's future placement in a group home or residential setting. We needed more time to work towards sustainable outcomes for Sarah and Ethan. With the series of case studies spanning across 18 months of field work, there was also a degree of pressure to complete the last case study. We subsequently agreed to terminate therapy.

3.6.4 Interview after psychotherapy had been terminated

Sarah's feedback about her experience of psychotherapy confirmed some of the clinical observations that I had made during the process of psychological intervention. She stated that she continued to experience high levels of parental stress that was centred on Ethan's behavioural difficulties and particularly his aggression. While she found it useful to discuss some of her parental challenges with someone *"who knows these children"*, our therapeutic efforts yielded limited success in the management of his behaviour.

Sarah attributed her improved mood and reduced sense of self-blame about her status as Fragile X carrier to psychotherapy and the self-disclosure of her feelings to relatives and acquaintances. Sarah told me that our conversations during the pre-intervention interview and first sessions made her realise that she was not to blame for Ethan's genetic condition.

She cited her newfound ability to say *"no"* to people who wanted to borrow money from her as the greatest therapeutic gain. However, although she was more assertive towards others in a rather specific area of concern, I did not get the sense

that Sarah's increased assertiveness was extended to other aspects regarding her social functioning. She also added that she continued to struggle to assert herself against Ethan.

3.6.5 Themes that emerged from thematic analysis

Theme	Excerpt
Parental stress and feelings of fear because of Ethan's autism-related problem behaviours that include aggression, routine inflexibility and poor impulse control.	<p>Sarah: I . . . (sound of truck reversing) I don't . . . know . . . how . . . bad, but, uh-uhm . . . like . . . more than once . . . I will wake up in my sleep . . .</p> <p>OC: [interjection] Ja.</p> <p>Sarah: . . . then I don't know what's going through his mind. He's sleeping, and I'm sleeping . . . and then he's biting me on my head.</p> <p>OC: Are you scared that he can hurt you to the point where you have to go to the hospital, or something like that? Are you thinking about it?</p> <p>Sarah: No, I haven't thought about the hospital yet, but . . .</p> <p>OC: [interjection] You're really scared?</p> <p>Sarah: I am scared.</p>
Parental stress, fear and health stress because of the potential impact of Ethan's behavioural difficulties on Sarah's physical health	<p>Sarah: . . . that it's arthritis, I'm just scared Ethan will bring me to that point that I will have a stroke.</p> <p>OC: Hm.</p> <p>Sarah: Because of the . . . chain reaction that's going through my head . . .</p> <p>OC: [interjection] Your head . . . I'm with you.</p> <p>Sarah: And then, uh-uhm . . . something might happen to me, then . . . he's alone with me in the house, he can't do anything . . .</p>
"He got it from me": Guilt and self-blame as depressive symptoms	<p>Sarah: . . . that he got it from me, even if I do feel guilty, because . . .</p> <p>OC: [interjection] Hm</p> <p>Sarah: . . . he got it from me. He's . . . I'm the reason he's like that, but then . . .</p>

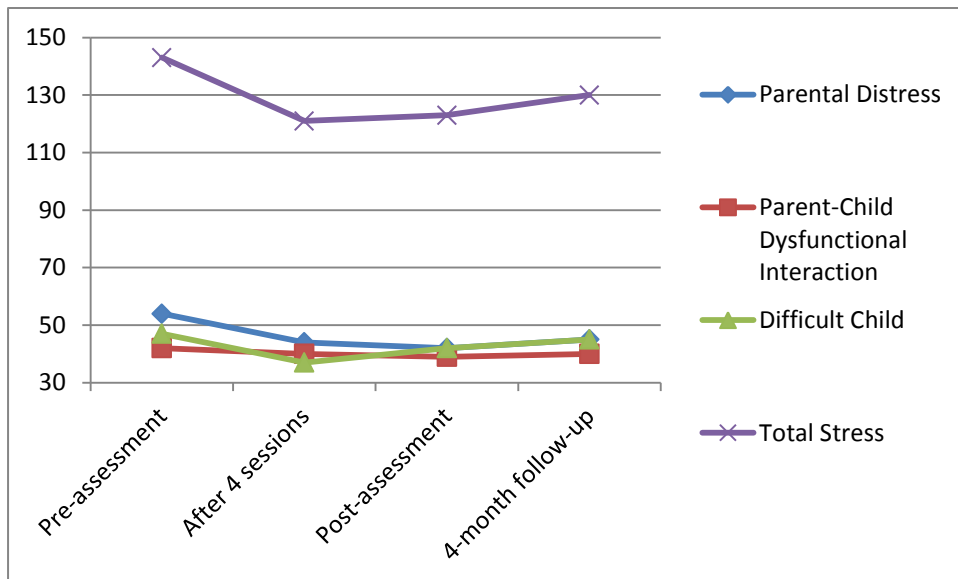
	<p>. uhm . . . the more I talk to people about it, the more it . . .</p>
<p>Helplessness and an external locus of parental control with regard to the management of Ethan's behavioural difficulties</p>	<p>Sarah: It's like . . . I dunno what his mind is telling him . . . I'm angry, at first it used to work, but now it's not working, me crying is not working anymore for him. Because he used to calm down when I start crying. But it's not working anymore.</p> <p>— Sarah: . . . and then sometimes it's not okay, like I said – Ethan decides what my day is gonna be like.</p> <p>— Sarah: It's just . . . he wants to go where he wants to go, and then I must just go with it.</p>
<p>Maternal mental health: Mild features of autism <i>Listing, "presenting", focused on topics that signified a limited scope of interest, and repetition of words such as "and then"</i></p>	<p>Sarah: . . . so I said: <i>"And when are you gonna pay me back the money?"</i> So she said: <i>"The end of the month, when I get my wages."</i> So I said: <i>"Oh. Then I can help you."</i> So I took out the money for her, and I gave it . . . an' then she brought us supper . . . two burgers, one for Ethan and one for me, from work, and she brought me two trays of doughnuts...</p> <p>OC: [interjection] Hm</p> <p>Sarah: . . . for the prayer meeting, and I asked ** [woman's name] to make scones for me, which I took with, an' . . . everything went . . . <i>nogal</i> (rather) okay for me on Tuesday, ** [woman's name] made us a chicken pie, she made a pot of soup for the prayer meeting, and . . . everything (recording equipment being touched) was just okay.</p>
<p>Feeling hurt and resentful about a perceived lack of support from family and relatives</p>	<p>Sarah: . . . they . . . uh-uhm . . . (shuffling) they only come see me when they need money from me.</p> <p>OC: Hm. Hm, hm.</p> <p>Sarah: [interjection] When they need something, an' . . . I'm not falling for it</p>

	<p>anymore. Like I said, ** [girls' name], uh . . . matric ball is the 17th of September, and I said I will see to a dress, but since they're not paying me what they owe me, I said . . . uhm . . . that's your own baby . . .</p>
<p>A dysfunctional and enmeshed parent-child relationship: Confrontive coping and resultant conflict, anger and coercive parental practices</p>	<p>Sarah:till I . . . cleaned the toilet. Right. Now I'm sitting on the toilet, now I'm watching Ethan standing in front of me there, and I think: <i>Gee whiz, Ethan, now why do you go on like this?</i></p> <p>OC: Hm.</p> <p>Sarah: Then . . . the . . . the . . . first thing that comes to my mind is: I just want to push him down the stairs. I can't put that on paper, it's not r . . . it's not right! And then . . .</p> <p>OC: [interjection] Hm</p> <p>Sarah: . . . now he's smiling at me, almost like that . . .</p> <p>— Sarah: Ja, because last week I took a plank and I hit him. Because he was kicking me . . .</p>
<p>Worrying about finances: non-assertive money lending and the cost of Ethan's snacks</p>	<p>Sarah: Yesterday I went to my cousin. And then . . . uhm . . . had s . . . they gave him juice, but like I said, it's . . . it's easy for me to say to ** [youngest daughter's name]: <i>"Just bring every time when you see there's little juice..."</i>, but I mean (feet shuffling): just to go on buying and buying just to . . .</p> <p>OC: [interjection] Hm</p> <p>Sarah: . . . satisfy Ethan is . . . it's very expensive.</p> <p>— Sarah: So, we went to town . . . the Saturday morning, and then I thought to myself: <i>'now why must I be . . .'</i> so, uhm, I went . . . on a purpose . . . and then . . . (pen clicking) they really took the joy of what I did, what I sacrificed that Saturday morning away from me, because I was thinking of them all the</p>

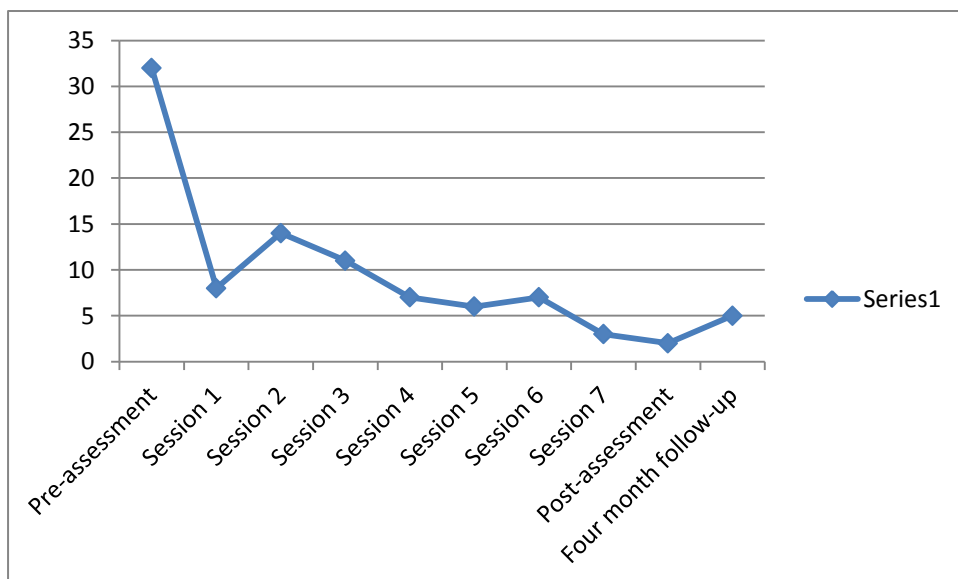
	<p>time, they now waiting on me, to have their car fixed. ** [Middle son's name]'s car is also standing . . . I phoned him, but he said: <i>"No, mommy, because we already owe you so much money, we mus' try to fix the car on our own."</i> His girlfriend is a PA, she earns a very good salary (bird chirping), but, they're young, they nice-time people (bird chirping). And, uhm (bird chirping), whenever I go, and then I can see (bird chirping), I've got to look on the other side of things also, then I will say: <i>"Come, take me to the shop</i> (page being turned), <i>an', just take whatever you need, an' I will pay for it."</i> (Papers rustling) And it's, look like they now taking advantage of the situation.</p>
<p>Examples of cognitive distortions</p> <p><i>All or nothing thinking</i></p> <p><i>Fortune-telling</i></p> <p>All or nothing thinking (Against evidence of events when Ethan accepted outcomes that did not go his way)</p>	<p>Sarah: All of my children. They're not coming to me.</p> <p>OC: ** [Eldest daughter's name, eldest son's name, middle son's name, Youngest daughter's name] is with you?</p> <p>Sarah: ** [Youngest daughter's name] is with me. Every time I phone ** [middle son's name] . . .</p> <p>Sarah: Because her children are going with, and uhm . . . so I said no, because they know I won't be able to enjoy myself if I take him with, because I don't know how he's gonna react.</p> <p>Sarah: Ja, because, uhm . . . the way he's acting is...he's too strong for me, and everything must just go his way</p>

3.6.6 Psychometric test results

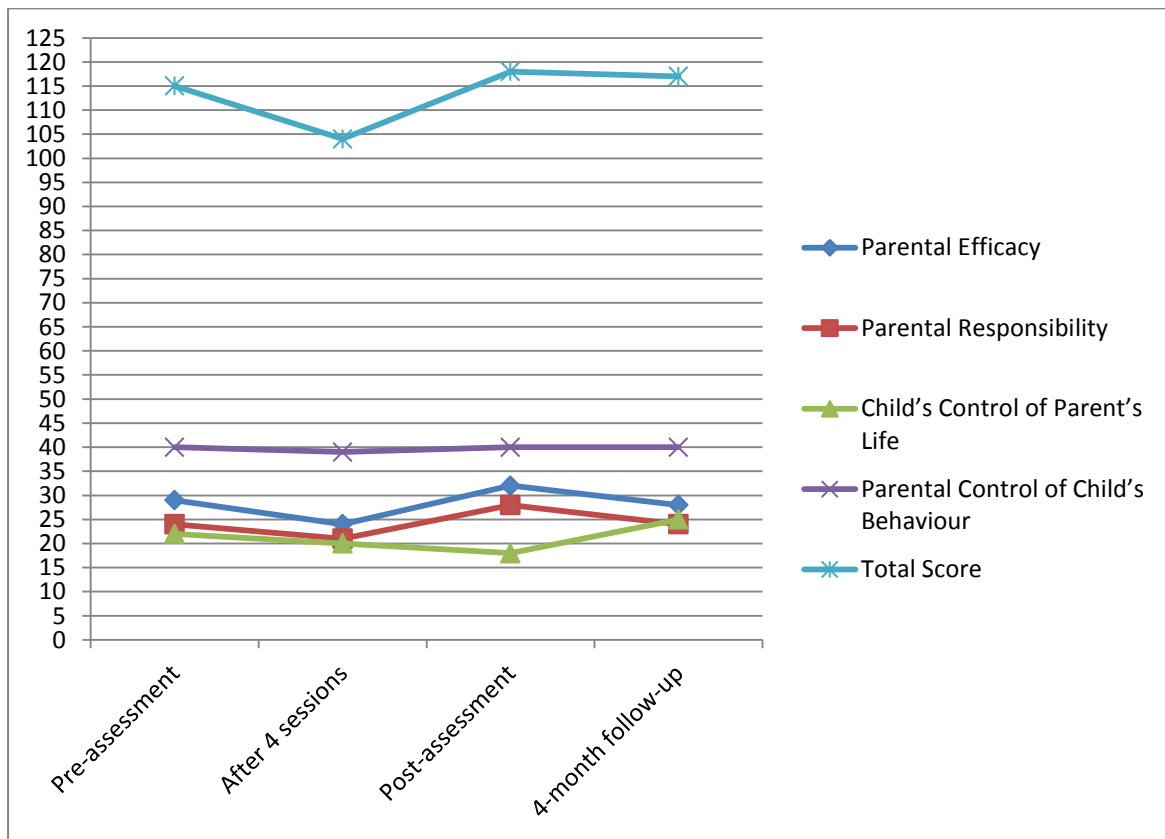
The Parental Stress Index: Short-Form (PSI-SF)



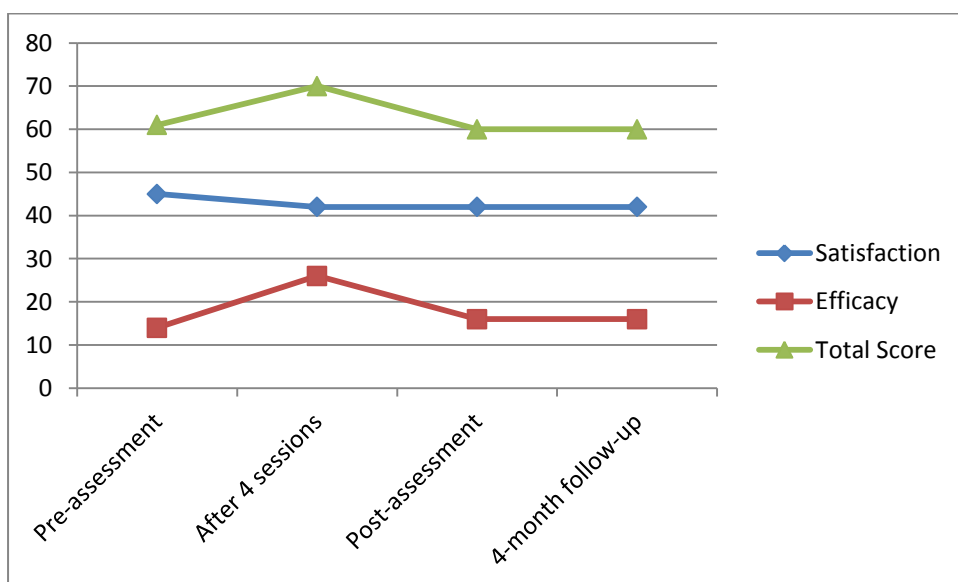
The Beck Depression Inventory II



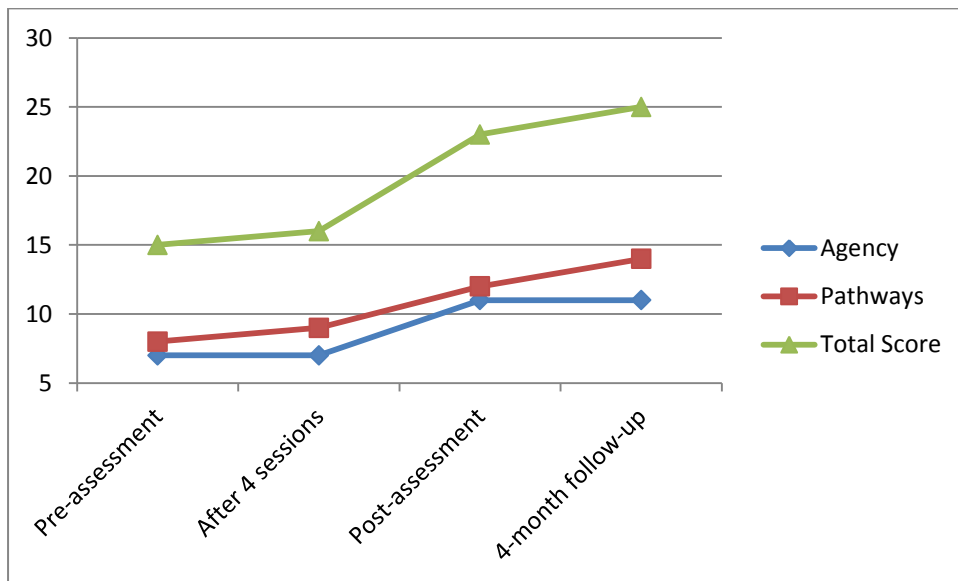
The Parental Locus of Control Scale



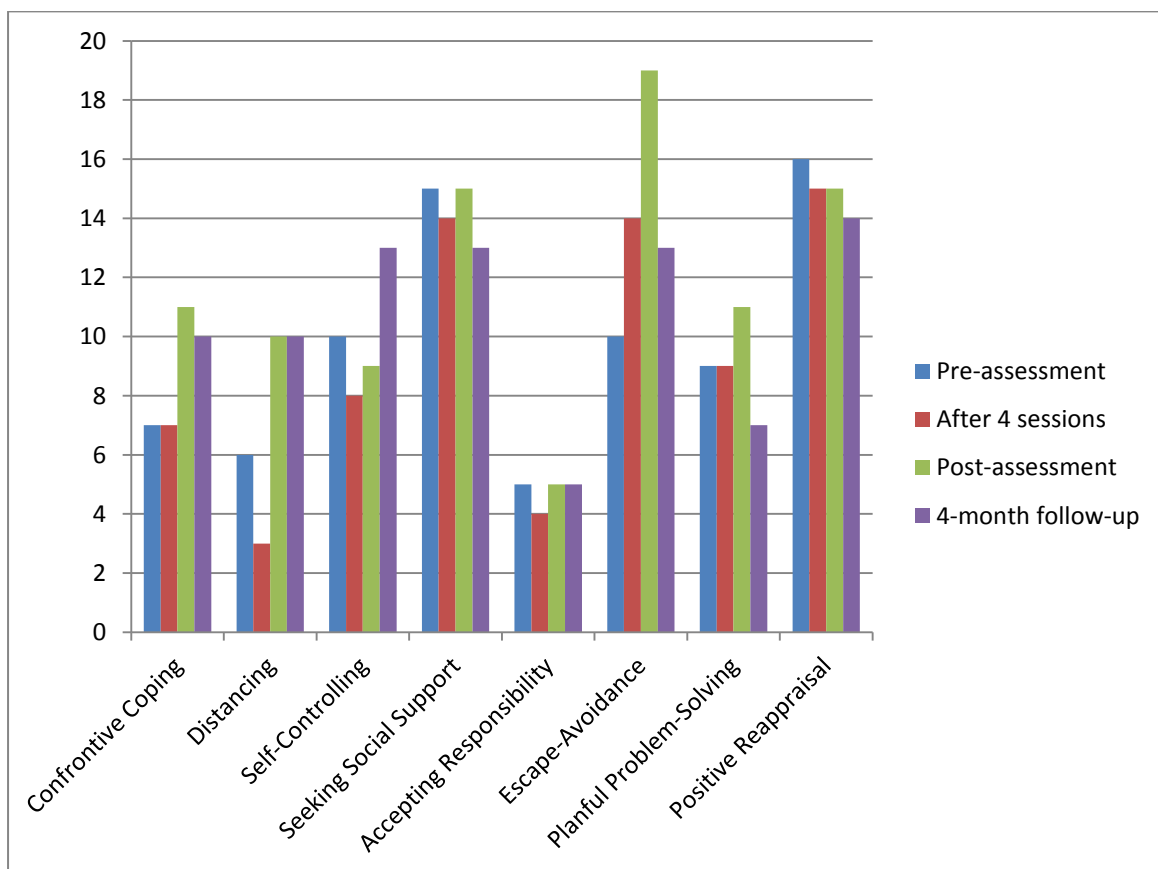
The Parenting Sense of Competence Scale



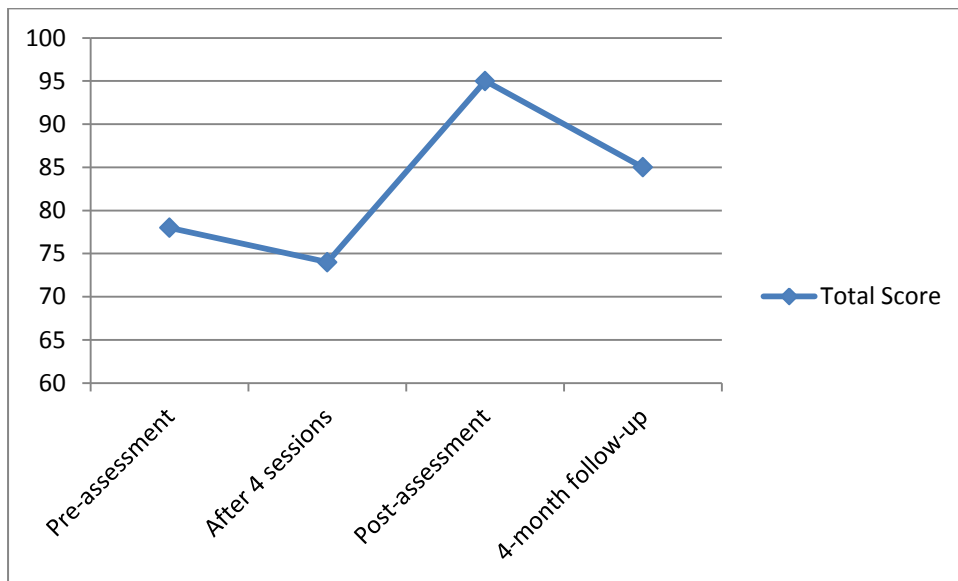
The Hope Scale



Ways of Coping Questionnaire: The Eight Ways of Coping



Ways of Coping Questionnaire: Total Score



3.6.7 Discussion

3.6.7.1 Sarah's psychological distress and challenges in coping: An argument in favour of a working diagnosis of mild features of autism

Sarah's amenability to psychotherapy should be considered against baseline autistic traits that had a pervasive impact on her psychological thinking. Although she was not formally assessed for ASD, a diagnosis of mild autistic features was provisionally made based on the observations that were written down in the narratives. As an ADOS-II administrator with experience working with children and adults who have autism, I had some appreciation of the diagnostic complexity that formed part of Sarah's conceptualisation. Accordingly, not all of her psychological problems could be attributed to pervasive developmental problems: She had a son with severe behavioural difficulties; retirement presented her with significant adjustment problems; she was treated for depression in the years before she attended psychotherapy; and she admitted to me that she felt alone and isolated even whilst attending her church's organised activities.

Previous genetic testing confirmed Ethan's diagnosis of Fragile X (full mutation) and Sarah's status as a carrier of the FMR1 premutation. Recent studies have refuted earlier research that found no correlation between the prevalence of autism and carriers of the FMR1 premutation gene (Bourgeois et al., 2009; Lachiewicz et al., 2010; Losh et al., 2012).

Contemporary studies have identified a higher prevalence of mild autism among mothers of children that were diagnosed with Fragile X. Research has also described a number of the autistic traits that some of the mothers with the FMR1 premutation presented with. Common features of autism among mothers included unusual eye contact, a plethora of pragmatic language difficulties, social anxiety,

difficulties in social interaction, and personality traits of inflexibility (Bourgeois et al., 2009; Lachiewicz et al., 2010; Losh et al., 2012). Deficits in executive functioning have also been reported, e.g., difficulties in planning, initiation, switching and perseveration (Bourgeois et al., 2009; Stirling, Mailick, Greenberg, Warren, & Brady, 2013).

Based on clinical observation and available literature, I believe that Sarah's mild autistic features had a fundamental impact on her ability to cope with interpersonal challenges, assertiveness, family conflict and Ethan's behaviour. It is also probable that the culmination of ineffective coping translated into elevated parental stress and maternal depression.

3.6.7.2 Parental stress, maternal anger and the dysfunctional relationship between Sarah and Ethan

As described in the foregoing section, I believe that Sarah's status as FMR 1 carrier might have made her more vulnerable to develop parental stress. More specifically, qualitative impairment in social interaction, pragmatic language difficulties and possible executive problems could have had a negative impact on her capacity to cope with Ethan's behavioural problems.

Sarah's FMR1 premutation could also *in itself* predispose her to greater levels of parenting stress when genetic vulnerability finds expression in problems with social interaction, rigidity and inflexibility.

Of course, Ethan's diagnosis of autism and his behavioural difficulties were also directly associated with Sarah's parental stress. Research has found that mothers of children who have autism tend to be more prone to experience high levels of

parental stress than parents of children who are diagnosed with other forms of disability (Dunn et al., 2001).

Ethan's repeated behavioural outbursts were linked with his own problems in terms of social avoidance, communication difficulties and other autism-related problem behaviours. It is probable that traits of Ethan's autism and subsequent behavioural difficulties were linked with Sarah's parental stress and their conflictual relationship.

I believe that a dysfunctional relationship evolved from their relational entanglement and Sarah's inclination to react angrily by lashing out at Ethan when he became aggressive. They essentially spent twenty-four hours of most days in each other's company, and Sarah had repeatedly described negative perceptions about Ethan's clinginess and constant presence in the kitchen, bathroom and bedroom. When she felt very despondent, she sometimes closed the curtains early in the morning and beguiled Ethan into believing that he should sleep because it was night-time.

Abidin (1995) considers a dysfunctional interaction style between parent and child as a discrete facet of parental stress.

3.6.7.3 *"They only know me when I have money"*: Sarah's perceptions of inadequate support

How could her children's avoidance and lack of support be explained? A possible explanation emerged from thematic analysis, and my understanding of Sarah's isolation within her family is also based on my countertransference towards her.

More specifically, our time in therapy was characterised by minimal social conversation. Sarah generally showed a lack of interest in topics that did not cover the subject matters she wanted to pursue.

I became progressively less and less subtle in my attempts to steer conversation away from Sarah's lists and soliloquised dialogue. At such times she tended to stop talking. Without making eye contact, she would then listen to me and pay attention to the topic I wanted to introduce. However, her listing most often proceeded immediately after I had completed my last sentence. Sarah used poorly-modulated social responses to let me know that she did not really want to pursue another line of thinking. She had a number of stereotypical social responses, e.g., *"Okay. Anyway, as I was saying . . ."*

As far as I remember, Sarah did not once make inquiries about my well-being at work or otherwise. I am as aware of boundaries as the next psychologist, but a polite *"How are you doing?"* or *"How are things at work?"* would not have been out of place, especially at the onset of our sessions and in reaction to my questions about her general well-being.

I believe that Sarah most likely had a similar style of engagement in her relationships with relatives and acquaintances. Her family might have experienced a similar lack of social responsiveness. Sarah's conversational topics may very well have more relevance to her own experiences, interests and worries than those of her family.

Besides a guilty conscience over money issues, it is therefore possible that her family's avoidance and lack of support were linked with Sarah's problems with social interaction and communication.

3.6.7.4 The use of a cognitive-behavioural approach to address Sarah's psychological problems

Sarah's parental stress was not significantly reduced by psychotherapy. However, I noted that Sarah was becoming more assertive towards her family by refusing to lend money to her children and other acquaintances.

The PSI-SF, administered at various intervals of intervention, failed to measure overall reductions of parental stress. While two of the three domains of the PSI-SF showed little improvement between pre-assessment and post-assessment (Parent Child Dysfunctional Interaction: pre-assessment = 42; 4-month post assessment = 40; Difficult Child = pre-assessment = 47; 4-month post-assessment = 45), Sarah's attainment on the Parental Distress domain registered modest improvement (pre-assessment = 54; 4-month post assessment = 45). Sarah's subjective symptom checks on parental stress also came down from a baseline of 80 to 40 after therapy was discontinued.

Sarah's results on the PSI-SF were in keeping with clinical observations: psychotherapy did not facilitate significant changes in the dysfunctional relationship between mother and child. In addition, Ethan's behaviour continued to be characterised by aggression.

Although her scores in the third domain of the PSI-SF showed modest improvement, I do not believe that Sarah's parental stress was significantly reduced by psychotherapy intervention. It is possible that reductions in depressive symptoms translated into slight therapeutic gain with regard to parental stress. However, Sarah indicated in the post-therapy interview that she continued to experience high levels of parental stress.

Psychotherapy was more effective in reducing depressive symptoms and Sarah was able to sustain her gains at 4-month follow-up (BDI-II pre-assessment = 32; BDI-II 4-month follow-up = 5).

As a carrier of the FMR1 gene, Sarah blamed herself as being the “cause” of Ethan’s disability; she also worried about her grandchildren and whether they would also have Fragile X. Thus, when discussion focused on her perceived responsibility as a causative agent, I repeatedly asked her if she could blame herself for “a faulty gene” she most likely inherited from her mother. Sarah subsequently told me that she felt considerably less guilt after she had realised that she could not blame herself for hereditary factors over which she had no control. BDI-II scores confirmed that initial reductions in guilt and self-blame were sustained through the course of therapy.

It is interesting to note that Sarah also started to explore Ethan’s group home placement options after therapy had been completed. The Hope Scale measured significant improvements in dispositional hope. Sarah took proactive steps to find placement for Ethan. At 4-month follow-up, Sarah told me that she continued to refuse giving her family money from her “*nest-egg*”.

Enhanced assertiveness was not, however, evident in her relationship with Ethan; and her sense of self-efficacy and parental competence remained very low. I believe that psychotherapy did little to reduce Sarah’s negative perceptions about the controllability of her son’s behaviour.

When describing Sarah’s lack of commitment to change her strategies when managing Ethan’s behavioural difficulties, I am careful not to use words such as *unwilling* and *reluctant*. Rather, my sense was that Sarah had real deficits in social judgement that prevented her from changing her way of managing Ethan’s

behaviour. As discussed earlier, her qualitative impairment in social interaction had an adverse impact on the parent-child relationship. By and large, it also prevented her from employing behavioural management strategies that hinged on self-reflection and the identification of trigger points in her own life.

CHAPTER FOUR: THEMATIC SYNTHESIS – RECURRENT THEMATIC CONTENT AND THE TRANSFERABILITY OF EMERGING THEMES ACROSS DIFFERENT CASES

4.1 Depressive Symptoms and the Manifestation of Guilt and Self-blame

4.1.1 Introduction

The previous chapter described relevant background information, predisposing, precipitating and maintaining factors, narratives of every session, the themes that emerged from thematic analysis and the psychometric results of each case study. In order to avoid unnecessary repetition because of the replication of themes across the six case studies, the discussion of each case covered interesting aspects and provided depth to some of the themes that were identified *within* each case.

This chapter will explore the themes that emerged from an analysis *across* cases, i.e., the replication of similar findings on a case-to-case basis.

4.1.2 “*Stuck in a rut*”: Depressive symptoms as a result of caregiving stressors that persisted over the course of time

As described in the first case study, Patricia presented with prominent symptoms of depression that had reportedly persisted over many years, including sadness, helplessness, hopelessness, fatigue and a loss of interest in activities that were previously enjoyed. In her own words, Patricia described her depression as follows:

Patricia: Very down. Like I say, the only uplift-upliftment I got is when I'm
?with the AA?, otherwise it's you just like I say exist . . . You exist in that
dome. You're not living. You're not happy, you know? You're not living...

OC: And it's stressful most of the week, every day?

Patricia: Most days. Most days.

OC: The biggest part of the day?

Patricia: The biggest part of the day and w-weekend, ?just down? all weekend.

I introduced the BDI-II as a clinical measurement of depression in four of the remaining five case studies because the battery of tests in the first case study did not include a systematic assessment of depressive symptoms. In a review that investigated maternal depression among parents of children who had DD, Bailey et al. (2007) have argued that research should clearly distinguish clinical diagnoses of major depression from descriptions of maternal symptoms of depression. Families of persons who have DD may present with negative affect and other symptoms of depression without meeting the DSM 5 or ICD-10 criteria of depressive disorder.

The BDI-II is by its authors' own admission an augmentative tool that should not substitute clinical observations and formal assessment by a trained psychiatrist or clinical psychologist (Bailey et al., 2007; Singer, 2006). I therefore decided to use the term "maternal depressive symptoms" when referring collectively to aspects of negative mood and other symptoms across the different cases.

I used my training as a clinical psychologist to assess symptoms of depression by using standard interviews and the relevant diagnostic criteria of the DSM-V (American Psychiatric Association, 2013). The BDI-II augmented clinical work and maternal self-reports. Depressive symptoms were accordingly observed in the profiles of Patricia, Linda, Hadil, Marlene and Sarah. Marlene's presentation was

more consistent with dysthymic disorder and clinical observation suggested that Sarah did not meet the full criteria of major depression.

As described earlier, all the transcripts of sessions and audio-recordings were made available to the clinical psychologist and psychotherapist that assisted me in peer supervision. She independently analysed the case studies of Patricia and Sarah and also went through the data of the other cases in a systematic manner. Another psychologist went through the written research material including the transcripts and narratives. Both psychologists concurred with my observations of depressive symptoms among the five participants. We also discussed the presence of severe major depression among Linda and Patricia in peer supervision.

It was noted that Patricia, Linda, Hadil and Marlene had struggled with depressive symptoms for an extended period of time that spanned over many years of caregiving. The four participants described formative life events and transactional experiences that were already taking place when their children were very young and sometimes before they were born.

Marlene was hospitalised and treated for depression before Karin was born and confirmed that she experienced depression before her marriage. As with the other participants, Marlene's memories were accompanied by feelings of intense sadness and emotional pain.

Patricia described herself as being "*stuck in a rut*" for decades following Sue's birth and the subsequent caregiving demands that were linked with Sue's high medical and behavioural support needs. She reported earlier parenting experiences that left her with pronounced feelings of sadness and helplessness because of her inability to prevent her daughter from having seizures. Patricia told me that she started to self-

medicate with alcohol because of her feelings of sadness and resentment. Besides her parental stress, she also believed at the time that she could not go on with her life; and she described a possible degree of dissociation when she told me she "*merely existed*" from day to day. Her caregiving demands left her with high levels of fatigue, low levels of self-confidence, and a sense of hopelessness about their future.

As described in the narratives, Linda and Hadil reported persistent rumination and feelings of sadness about the loss of a healthy child. Linda described this longitudinal process of "*coming to grips with*" as follows:

Linda: Uhm, I still can't accept it. Uhm, seeing Tony from being a healthy child turning into the state that she is today isn't easy to accept. Tony's slowly deteriorated. It's not . . . how can you say it? It was slowly going downhill.

Hadil's sense of loss and grief extended to her three children who were diagnosed with RP. The onset of Ashraf's schizophrenia further compounded Hadil's negative affect. In both case studies, the negative emotions and symptoms of fatigue and exhaustion persisted for longer than a decade. Hadil repeatedly stated that her caregiving tasks were "*too much*". She felt hopeless about the future, believing that her other sons will refuse to provide caregiving to Ashraf after her death. Her rapidly deteriorating physical health because of diabetes mellitus and lupus erythematosus fuelled helplessness and hopelessness.

Hadil's experience of a lack of family support and depression are in keeping with the findings of a study that explored caregiving experiences among compounded caregivers, i.e., caregivers who are tasked with the care of two or more individuals with disability (Perkins & Haley, 2010).

Among the five participants, contemporary reports of sadness, helplessness, hopelessness, a loss of interest, difficulty in concentrating, fatigue and suicidal ideation (Linda) were often linked with the demands of present-day caregiving challenges that included their children's aggressive behaviour.

Patricia attributed her depressive symptoms to Sue's repetitive behaviour, demands and aggression. Linda gave maximum ratings for depression because of Tony's aggression and other conflict situations in her life that left her with feelings of sadness and guilt. Her reluctance to have Tony back at home also contributed to her negative mood. At such times she pictured herself putting a hosepipe in the exhaust of her car to put an end to her and Tony's lives. Hadil's negative mood was linked with the recent loss of her youngest son's vision, but also with Ashraf's relapse into psychosis, his peculiar behaviour and his admission into hospital. Besides other negative family events with her other children, Sarah experienced feelings of sadness and despondency because of her conflictual relationship with Ethan.

Marlene's stressors diverged from the other participants because a relatively heavier attribution loading for negative affect and depressive symptoms was placed on her relationship with Leon (as opposed to Karin's relapse into mania and her daughter's subsequent aggression):

It is important to note that constant caregiving challenges and the management of their children's aggression left Patricia, Linda, Hadil and Sarah with depressive symptoms *and* elevated parental stress. Their underlying belief system often reflected cognitive distortions about contemporary caregiving challenges. As I will

describe later, many of these beliefs were embedded in caregiving schemas that had developed from the earlier parental experiences that I described.

Based on reports of depressive symptoms that prevailed through the course of years of caregiving, a “pile-up” of negative caregiving events with expressions of negative mood and helplessness were evident (Kim et al., 2003, p. 314). The pile-up of life stressors and my observations of clinical depression along with maternal reports of depressed mood gave credence to the accumulative stress theory that was described in the literature review. Also referred to as the “wear and tear” theory (Rowbotham et al., 2011, p. 130), it is posited that repeated maternal exposure to adverse caregiving events would result in an increased subjective burden of care (Awad & Voruganti, 2008; Hall et al., 2012; Heller et al., 1997; Minnes et al., 2007; Rowbotham et al., 2011).

Against these views, proponents of the adaptation model argue that parental stress and depressive symptoms will subside over the course of time. According to the adaptation model, parental well-being will improve because the child's behavioural problems tend to dissipate with age; and parents gradually accept their children's status of having ID. Furthermore, habit formation in adulthood and subsequent gains in the predictability of behavioural outcomes in adult children would conceivably also reduce parental stress (Haveman et al., 1997; Heller et al., 2007).

It is important to note that the profile of the children of participants was unequivocally different from the fundamental suppositions on which the adaptation model rests: Aggression did not abate as the child grew older; and mothers had to deal with their children's aggressive behaviour as well as other behavioural difficulties on an ongoing basis.

Furthermore, the children of Linda, Hadil, Sarah and Marlene spent most of their days at home without attending vocational training, sheltered employment or other development programmes. Only Patricia's child attended a workshop.

At no time throughout therapy did parents report a sense of relief because of perceived stabilisation in the routines of their children. Rather, parents were faced with many caregiving responsibilities and other daily living requirements that demanded their time and energy.

In fact, in South Africa, persons who have ID may often finish their schooling without having realistic prospects of finding suitable sheltered employment or another form of vocational training due to a scarcity of resources (Adnams, 2010). There simply are not enough vocational services for adults who have ID. Participating mothers also repeatedly voiced their frustration about the unwillingness of sheltered employment services to consider the placement of persons who display marked problem behaviours:

Karin's psychiatric and behavioural problems made further attendance to a workshop unsustainable; Ashraf had spent most of his time at home for many years; and it has been more than five years since Tony's cognitive decline and escalated behavioural problems led to a breakdown of her placement at a sheltered employment setting. At the time of therapy, Ethan had completed school the year before and boredom was a prevailing precipitant to many of his oppositional and aggressive behaviours.

The next section will analyse maternal expressions of guilt and self-blame, constructs that could be respectively seen as affective and cognitive manifestations of depression. I decided to discuss guilt and self-blame under a separate heading because of their thematic prominence across the different cases.

4.1.3 “*I am at fault*”: The potency of earlier parental experiences on here-and-now assertions of guilt, shame and self-blame

Thematic analysis elicited expressions of guilt, shame and self-blame among all six of the participants. As described in the narratives, the participating mothers often reported feelings of guilt towards their children because of different contemporary caregiving events. At other times some of the participants presented with attributions that they were at least in part to blame for their children’s disability or medical condition. They therefore felt guilty towards their children who had disability, but from time to time such feelings of guilt and self-blame also extended towards other family members.

The abovementioned beliefs often manifested as negative automatic beliefs and cognitive distortions. Hadil and Linda's beliefs that they were to blame for their children's physical and/or intellectual disability were based on arbitrary inference, selective abstraction and perhaps even personalisation: there was no evidence to suggest that Tony's minor accidents, falls during infancy or Linda's parenting led to her daughter's organic impairment and the development of epilepsy.

Hadil's repeated descriptions of guilt and self-blame were also based on beliefs that were not grounded in empirical evidence. The emotional reasoning behind the following statement is clearly discernible:

Hadil: So since the kids came it’s been going downhill. It’s like . . . I mean, I’ve been robbed of my happiness, you know? But there was a time when we were separated, me and my husband.

OC: Mm.

Hadil: For a very while . . . long while, because I felt it's my fault . . . All this is my fault! And I felt he deserves some happiness.

OC: Ja! Guilty? You felt guilty?

Hadil: No, I felt terribly guilty. Although he tried to tell me: "*Look, it's not your fault!*" But I deep down knew it's my fault! Up to today I keep on blaming myself. I don't know why!

Thematic analysis suggested that many of the cognitive distortions that led to feelings of shame and guilt were based on fundamental, core beliefs about parenting. The development of many of these beliefs could be traced back to earlier parental experiences. I use the word "earlier" in a somewhat loose manner to depict events that occurred years before the child had reached adulthood:

As described, Linda and Hadil believed that they were to blame for their children's disability while their offspring was growing up. Sarah's internalisation of guilt for being a carrier of Fragile X had correspondingly left her with guilt and beliefs that she was responsible for her son's ID and autism. Patricia described feelings of guilt for not being able to do anything to help her young daughter while she was having seizures.

As described earlier, Patricia stated that her progressive lapse into substance abuse and her husband's battle with addiction had negative ramifications on their parental capacity to meet demanding Sue's strenuous caregiving requirements. While Patricia openly acknowledged her feelings of sadness about caregiving events at the time, she was less forthcoming about her feelings of regret, shame and guilt. Her feelings of sadness and guilt were instead related to their decision to place their

daughter in a residential centre. She also had strong negative emotions about the chaotic home circumstances and parties that took place when Sue went home for weekend visits. In this regard, Patricia also regretted that they "*spoil*" Sue during these visits. Besides other factors, Patricia was of the opinion that Sue's present-day oppositional behaviour was the result of their lack of limit setting and boundaries during weekends.

Marlene repeatedly mentioned that she felt guilty about not leaving her first husband earlier in their marriage, thereby exposing her children to abuse.

Marlene also believed that IPV was directly responsible for her daughter's premature delivery and resultant cerebral palsy and ID. She was left with a sense of despair when her daughter was born. She told me that she prayed and asked God to let her child die after she had seen her daughter's physical disability and re-experienced the trauma that led to her daughter's birth:

Marlene: In the back of your mind! And I mean, by birth I said: *Lord, why not take this child away?* Because it's-it's . . . it looked like an animal-kind-a-thing, you know? This small child . . .

OC: Mm?

Marlene: And not even cry properly! And only after three days I went to see him. I even asked God to take her away when I go and pray, uhm . . . How will I cope with a small child and that? But she kept on living . . .

OC: Attachment took place.

Marlene: And just one of the mothers said to me: "*My child, it doesn't matter where you pray . . .*" I mean, she had a sitback [sic] after a month; then she

had a brain-bleeding [sic]. And I said: Now this isn't right! So I was talking to God while I was sitting in the toilet, praying. (laughs)

However, Marlene also told me that such feelings were soon replaced by love and a sense of guilt that she had those ideas to begin with. She added that she processed most of her feelings of guilt and shame through the counselling training courses that she attended.

I do not claim that the earlier parenting events that were described in the previous paragraphs were somehow directly responsible for contemporary expressions of maternal depression, especially with regard to guilt, regret and self-blame. While most of the participants continued to recall many of these events with visceral clarity, I got the sense that the participating mothers had generally accepted the reality of their children's intellectual disability and medical problems.

Although many of the participants might have continued to experience varying degrees of guilt about their children's diagnoses of ID or medical illness, most of their guilt and self-blame appeared to revolve around caregiving incidents that had happened at the time when therapy took place. I believe that the earlier parental experiences may have *sculpted* their contemporary parental reactions to adverse caregiving incidents.

I can now consider *how* earlier parental experiences could possibly have shaped more recent perceptions of distressing caregiving events. The diathesis-model and cognitive theory of depression provide theoretical accounts of the potential influence of earlier events on a person's cognitive processing of contemporary events (A. Beck & Alford, 2009).

The diathesis-stress model proposes that a person's vulnerability to develop a first episode of depression or experience relapse increases exponentially if dormant depressogenic schemas are activated during adverse life events (A. Beck & Alford, 2009). Schemas are cognitive variables that consist of fundamental beliefs and could be described as "relatively enduring internal structures of stored generic or prototypical features of stimuli, ideas, or experiences that are used to organize new information" (Clark, Beck, & Alford, 1999, p. 79, as cited in Seeds & Dozois, 2010). Stated differently, schemas comprise guidelines and more rigid imperatives that assist a person to deal with novel input from their environment (Wright et al., 2006).

Simple schemas refer to natural scientific laws or predictable outcomes in routine activities, e.g., the rising of the sun in the east or the expectation that a vehicle will accelerate when pressure is applied to the petrol pedal (A. Beck & Alford, 2009; Wright et al., 2006). Intermediary and core beliefs are two other forms of schemas. Intermediary beliefs could be described as self-regulatory attitudes, assumptions and rules that reaffirm or disaffirm aspects about the self, other people or the environment (J. Beck, 1995).

Together with intermediaries, core beliefs are schemas that could be described as "the most fundamental level of belief; they are global, rigid and overgeneralised." (J. Beck, 1995, p. 16).

When focusing on parenting schemas or core beliefs of parenting that developed from earlier parental experiences, the following should be considered:

First, core beliefs are most often shaped during early childhood by formative influences such as the child's relationship with adult authority figures. Core beliefs could also develop from other traumatic events, successes and significant life events

that were staggered along the developmental pathways of a person's life (A. Beck & Alford, 2009).

Depressogenic schemas will incorporate negative beliefs about the self, the environment and future (A. Beck & Alford, 2009). Also called the cognitive triad of depression, core beliefs among people who are vulnerable to depression may include statements such as *I am incompetent; I am inadequate; my future looks bleak; and I am to blame.*

Second, negative core beliefs are often seen as appropriate reactions against dysfunctional, traumatic or abnormal events that had occurred in early childhood. Such core beliefs are sometimes problematic when a person used her schemas as templates to evaluate recent events of a similar nature. In such instances, the cognitive templates that developed during formative years could result in distortive thinking if the circumstances regarding contemporary events changed markedly (A. Beck & Alford, 2009).

Third, core beliefs are not immutable and CBT holds the restructuring of negative automatic thoughts, intermediaries and core beliefs as a central tenet (A. Beck & Alford, 2009; J. Beck, 1995).

Self-Discrepancy theory considers maternal guilt and shame as end-products of disparate parental perceptions that differentiate between the ideal and real self (Liss, Schiffrin, & Rizzo, 2013). Mothers develop shame when they evaluate their parental conduct (real self) as being deviant from societal norms and expectations (ideal self). Conversely, self-observed differences between a mother's personal parental principles and eventual parental practices may result in feelings of guilt when her

parenting behaviour fails to meet the standards she set out to achieve (Liss et al., 2013).

In the context of the present study, I will now consider the influence of earlier parental events on contemporary maternal experiences of sadness, guilt, shame, helplessness, hopelessness and anhedonia.

With the exception of Jeanette, all of the participants reported distressing and traumatic parental experiences that occurred around the time when their children were diagnosed with ID or a chronic medical condition such as epilepsy. As I described earlier, some of these mothers also lived in adverse social and familial circumstances at the time of becoming aware of their children's disability or medical illness, e.g., IPV and severe marital acrimony.

It will not be far-fetched to argue that Patricia, Linda, Hadil and Marlene were faced with family crises at the time. Although less pronounced, Sarah also described a period of dysphoria after Ethan had been diagnosed with autism.

I believe that five of the six participants developed core and intermediate beliefs about different aspects of their parenting during these earlier times of crises. I will elaborate later in this chapter on the interesting point that, among some of the participants, schemas of depression appeared to have already been in place when their young families went into crises. As described throughout the different narratives of cases, negative parental core beliefs included the following:

- *I am to blame (for my child's disability/illness).*
- *I am unable to protect my child.*
- *I am a bad mother.*

- *I cannot cope with a disabled child.*
- *My child is my responsibility only.*
- *I am inadequate (as a parent).*
- *I am defective and so is my child.*

It is conceivable that Patricia, Hadil, Linda and Marlene inferred during the earlier stages their parenting that they were unable to protect their children and ensure their offspring's health and safety. Patricia and Linda told me they were unable to prevent their children's seizures; and Hadil knew that Ashraf had RP before he inevitably started to lose his eyesight. Marlene was exposed to severe IPV and she was constantly fearful for the safety of her children.

It is plausible that the abovementioned experiences left these mothers with feelings of guilt and self-blame. In a very real sense, they would have most likely felt bereft from the often unspoken aspirations and dreams that young mothers hold about their unborn children.

Although time had allowed Patricia, Linda, Hadil, Sarah and Marlene to process many of their earlier parental experiences, the formation of core beliefs of blame and its accompanying feelings of guilt or shame continued to play a role in their assertion of *contemporary* caregiving events. Moreover, schemas of depression were activated by contemporary caregiving stressors that resembled or reaffirmed some of the core beliefs that I described in the preceding paragraphs.

Examples include Linda's ambiguity and guilt after Tony was admitted to hospital, albeit that she also felt relieved to be offered some respite. Linda told me that God gave her *"this cross to carry"*; she said she felt guilty because she now expected *"other people to look after my child"*.

In Linda's case, she also felt ashamed and guilty after Tony's behaviour at hospital had returned to baseline. She told me that the attending doctor and nurses did not believe her – she was worried that these health care professionals would think that she admitted Tony *“just to get rid of her.”*

In truth, Linda made it explicit that she wished that Tony was placed permanently in a group home. The subsequent beliefs of self-blame were linked with formative experiences that evoked similar feelings of guilt. Core beliefs included: *I am a bad mother; I am to blame; and I am inadequate.*

Patricia's steadfast refusal to exclude Sue from social activities notwithstanding a growing resentment towards her daughter serves as another example. On the one occasion that Patricia decided not to take Sue to a social gathering, her response was as follows:

Patricia: So . . . (long pause). I've been feeling guilty for . . . so long . . . And, not doing what I should do . . . Living my life, and, uhm . . . Ja! (sighs heavily). And that's just for today. I've never taken her with. I mean I've always taken her with, never thinking of myself only. (Long pause)

Hadil's reported dysphoria and uncritical acceptance of her brother-in-law's rebuke about her perceived neglect of Ashraf's care were also based on feelings of guilt and fundamental beliefs that she was to blame. Marlene's oscillation between non-assertive appeasement and angry confrontations during her conflict with Leon was directly linked with feelings of guilt when she did not provide him with petrol money or meet other requests, even though she resented many of these requests.

As described in the narratives, contemporary conflict with Leon often led to her son blaming her about the abuse he had witnessed when he was a child. The following excerpt was taken from a longer process in which we identified and eventually modified some of the beliefs that Marlene had about Leon's accusations and their conflict: The excerpt also captures some of her ongoing feelings of guilt:

Marlene [interjection]: He (Leon) said it to me! I'm a bad mother!

OC: And he said to you that you're a bad mother. So your thought . . . your automatic thoughts were . . . ?

Marlene: A bad mother!

OC: A bad mother. And that made you feel?

Marlene: Guilty.

OC: Okay, so there we go. That's just where I want to keep it right now. Let me just write it down, because I write like a . . . I have a terrible handwriting.

Uhm . . . 'Event'. I'm just gonna write here: (writing it down) Leon . . . talks to me. . . talks to me and blames me for everything. (long pause) Your automatic thought . . . So the event led to automatic beliefs along the lines of: I am . . . a bad mother. Bad, bad mother.

Marlene: No, you can say bad, bad, bad! (laughs)

OC: Bad, bad, bad . . . ad infinitum.

Marlene: (laughs)

4.1.4 The use of cognitive-behaviour therapy to reduce symptoms of depression

The BDI-results and clinical observation suggest that four of the participants responded positively to therapeutic efforts aimed at reducing symptoms of maternal depression. The results from follow-up assessment suggest that Linda, Hadil, Marlene and Sarah maintained many of the gains that were reported in the previous chapter. Patricia's mood improved only after selective serotonin reuptake inhibitors were introduced.

Before describing the use of CBT in more detail, I would like to briefly explore caveats against claims that psychotherapy was responsible for reductions in depressive symptoms among Linda, Hadil, Sarah and Marlene:

First, it is possible that Linda, Hadil, Sarah and Marlene completed post-psychometric assessments in a deliberately favourable fashion because of an idealised countertransference (Kohut, 2009; McWilliams, 2011). However, Sarah's PSI-SF scores suggest that her parental stress was not significantly reduced by psychotherapy. Hadil was also unable to maintain her gains with regard to parental stress at 4-month follow-up. When considering the possibility of an idealised countertransference, I doubt whether both Sarah and Hadil reported improved mood as positive therapeutic outcomes whilst neglecting to portray other therapeutic measurements in an equally favourable light.

It is possible that Linda and Marlene amplified their therapeutic gains across different measurements at post-assessment, but clinical observations and their feedback during the post-assessment interviews suggest that psychotherapy played a positive

role in reducing depressive symptoms and parental stress. In addition, BDI-II scores generally corresponded with the thematic content of sessions. For example, Marlene started to respond with lower ratings of depressive symptoms directly after we addressed some of the issues regarding her conflict with Leon.

Sarah considered her lower feelings of guilt and self-blame about her status as carrier of the Fragile X premutation gene as her greatest therapeutic gain. As mentioned in the previous paragraph, her parental stress showed little improvement.

Last, as I mentioned earlier in the chapter, it is possible that Tony and Ashraf's hospital admissions provided respite to Linda and Hadil. It is therefore possible that their reports of lower parental stress and improved mood were the result of respite and not psychotherapy. The previous chapter described Hadil's distress and worry about Ashraf's well-being following admission. It is unlikely that respite afforded her a break from caregiving because she was also providing care to her other children and mother-in-law.

I have little doubt that Tony's admission contributed significantly to Linda's improved mood and her lower levels of parental stress in particular. Yet I also believe that psychotherapy assisted in lowering her feelings of guilt, self-blame, sadness and some of the negative symptoms of depression. As part of her homework assignment pertaining to behavioural activation, Linda started reading again. I met her in the waiting room of the Out-Patient Department months after she had completed therapy. With a voluminous paperback novel in hand, she told me that she continued to read late into the night.

A more substantive argument, however, lies in the past-oriented focus of the therapeutic work that Linda and I endeavoured to complete. On a fundamental level,

I believe that Linda shifted after we had disentangled and systematically covered unfinished business that dated back to her formative parental experiences. Linda worked through some of her experiences of loss that she had never fully processed before. I am not claiming that therapy was exclusively responsible for her improved mood. However, the successful refutation of beliefs that she was to blame for Tony's epilepsy was quintessentially therapeutic.

In fact, I would like to argue that psychotherapy lowered depressive symptoms among four of the participating mothers by refuting some of the schemas of depression that were responsible for contemporary experiences of guilt, regret, shame and self-blame.

Rudimentary psychoeducation allowed Linda, Hadil, Sarah, and to a lesser extent Marlene, to renegotiate their beliefs that were based on global attributions that they were (at least partly) to blame for their children's epilepsy, genetic disorders or psychiatric illness. I believe that cognitive restructuring replaced some of these beliefs with a more nuanced understanding of the biological aetiologies of schizophrenia, Fragile X and epilepsy.

I strived to co-create collaborative therapeutic relationships and strong alliances with all the participants. I also tried my best to co-create therapeutic relationships that were founded on mutual trust and unconditional positive regard in order to facilitate therapeutic change (e.g., Bateman, Brown, & Pedder, 2010; A. Beck & Alford, 2009).

Although it will be difficult for me to substantiate, I would like to believe that therapist responsiveness and a collaborative therapeutic relationship countered some of the critical, shameful and at times abusive feedback that Linda, Marlene and Hadil had received from a small minority of healthcare professionals. It must have really been

hurtful to hear their children being described as “*brain damaged*”, “*that fat thing*” and “*a vegetable*”.

4.1.5 Clinical implications: Towards a distinction between depressive symptoms and parental stress

The present study has conceptually separated symptoms of maternal depression from parental stress for pragmatic reasons. A short exposition will now be provided to explain my motivation behind the decision to divorce the two concepts. I am hopeful that a degree of clarity will be obtained which will provide further structure and direction to the remaining part of the chapter.

In a meta-review, Hayes and Watson (2013, p. 629) have criticised the indiscriminate use of depressive symptoms as a by-proxy measure of maternal stress. They asserted that parental stress results from distressing caregiving experiences that are linked with parental practices and other aspects of parenting. Conversely, a plethora of contextual and biological factors may be responsible for maternal depression, e.g., a genetic predisposition (A. Beck & Alford, 2009), socio-economic status (e.g., Singer, 2006), and physical health status (Chou et al., 2010). Importantly, many of these factors fall outside the admittedly fluid parameters of parenting.

Parental stress is a concept that is based on different coping models (e.g., Folkman & Lazarus, 1988; Johnston & Mash, 1989; McCubbin & Patterson, 1982). The process model of coping defines stress as the result of cognitive appraisals that the stressor “exceeds” or “taxes” a person's available coping resources to deal with the distressing situation (Folkman, 1984, p. 840).

In this context, the consequences of ineffective or inadequate coping could include possible depressive symptoms and other negative emotions such as anger, embarrassment and shame (Hayes & Watson, 2013).

In this study, the conceptual distinction between parental stress and depressive symptoms was therefore maintained:

As described in the previous chapter, thematic analysis revealed that parental stress was most often maintained by distressing aspects of parenting, e.g., the parent-child relationship, the child's behavioural difficulties and inadequate parental coping resources to deal with distressing caregiving events.

Conversely, as described in this section of the chapter, contemporary beliefs that were linked with maternal depression were often activated by depressogenic schemas. Such schemas tended to develop from *earlier* parenting experiences and the formative influences of the parent's childhood. The aetiological base and maintaining factors of parental stress were more firmly embedded in *recent* caregiving experiences and the child's ongoing behavioural difficulties.

Lastly, psychometric measurements of depression and parental stress sometimes highlighted different therapeutic outcomes between maternal stress and mood-related symptoms in the same participant. For example, Hadil sustained her measurements of improved mood on the BDI-II during follow-up assessment. She told me that she continued to feel less depressed. However, she relapsed on measurements of parental stress. Likewise, Sarah responded with lower levels of depressive symptoms on the BDI-II, but her PSI-SF scores suggested little improvement with reference to parental stress.

I am not repudiating the fact that there appears to be considerable overlap between parental stress and maternal symptoms of depression. Inadequate coping resources such as a limited sense of self-efficacy and poor problem-solving skills may indeed predispose a person to develop depression and high levels of parental stress. In addition, prolonged exposure to demanding caregiving stressors may also result in an accumulation of parental stress that perpetuates and maintains depressive symptoms (e.g., Heller et al., 1997; Singer, 2006; Singer et al., 2007).

Psychotherapy subsequently challenged participants to evaluate the empirical validity behind some of their depressogenic schemas; and in some instances depressive symptoms became less pronounced as a result. As I will demonstrate in the next section, it was more difficult to lower parental stress and negative perceptions about the children's behaviour.

4.2 Exploring Stressful Caregiving Demands and the Child's Behavioural Difficulties: Parental Stress and its Associated Constructs

4.2.1 Introduction

On baseline, PSI-SF measurements confirmed elevated levels of parental stress among all five the participants that completed the questionnaire. Jeanette provided high ratings of parental stress during the first session.

The participating mothers appraised many of the stressful caregiving encounters as threatening, challenging or potentially harmful (Folkman, 1984; Folkman & Lazarus, 1988; Glidden et al., 2006; Kelso et al., 2005; Lazarus, 1999; Paster et al., 2009). Thematic analysis elicited negative and distressed parental reactions against the child's behavioural difficulties across all the cases. Parents often described heightened levels of parental stress when the following occurred:

- Episodes of the child's aggression that were directed towards the mother, relatives or strangers.
- Maternal observations of threatening cues that led to the anticipation of aggressive outbursts.
- Deterioration in the child's behaviour in terms of frequency, severity, duration or the amount of by-product.
- When the real or potential consequences of behavioural difficulties were negative, e.g., if Sue's destructive behaviour led to criticism from Patricia's relatives about her management of Sue's behaviour.

4.2.2 Parental stress and the child's behavioural difficulties: *In situ* distress, worry and apprehension

Five of the six participants described the negative consequences of their children's aggression in their own lives. The following excerpt brings together different aspects of the child's behavioural difficulties that led to distressing maternal reactions across different cases:

Linda: Uhm, you always walking on eggs. You don't know what you're going to expect from her! She may seem calm and mild and at ease at the moment. But on the spur of the moment she can just turn around, start shouting at you, screaming at you for no reason!

OC: Mm.

Linda: Her . . . and especially in public . . . When she knows she's got an audience. You have to be so careful not to annoy her or go against her!

OC: Ja!

Linda: Because she will throw a tantrum!

OC: Mm.

Linda: So you have to be careful all the time around her of what you say, what you do, what your actions are, even if you don't . . . speak to her! You're speaking to somebody else. She'll see it as an attack on her!

OC: I know! Okay. Mm?

Linda: So it's stressful to live like that. I'm tensed up all the time!

OC: Has . . . Okay, has it been like that for years and years, or has it recently gone just very much worse?

Two: The last . . . (sighs heavily) . . . three years it's become worse.

OC: You see there's some . . .

Linda: The way . . . when her psychosis increased; when she . . . Ja, her behaviour gets *ba* . . . gets worse. And I don't know!

The excerpt highlights the unpredictability of some of the outbursts, something that Patricia, Jeanette, Sarah and Hadil also mentioned. I should immediately add that most of the children's outbursts had observable cues from identifiable triggers. The internal cues of aggression in the profiles of Tony, Sue and Ashraf were at times more difficult to trace, i.e., Tony's non-convulsive seizures and the delusional and/or obsessional fixations of Sue and Ashraf.

Linda's use of the word "*always*" and the phrase "*all the time*" pointed to distortive generalisations and magnifications that highlight the continuous threat value of potential outbursts. As a result, constant vigilance and monitoring were required. The helplessness of not knowing how to manage the behaviour is also evident in the excerpt. Of course, Tony was not always aggressive but her aggression was at times erratic if she was having non-convulsive frontal seizures.

As described in the narratives, Linda disclosed high levels of parental stress at other points in therapy. For example, she felt helpless when her parents phoned her while she was at work to complain that Tony was threatening her father with a knife.

Patricia often elaborated why she gave high ratings to symptom checks of parental stress:

Patricia: So, I made her a cup of tea. I said: "*Sue, the tea is on the dining room table.*" And she passed me, and she swung around: "*What'd you say? What did you say?*" And she just went ballistic. I said to her: "*The tea is on the dining room table.*" And to me, she heard something else. Because she was angry with me! "*Don't say that!*" You know, that type of thing? So I

explain to her again, but I'm shaking out because I'm scared, because she's gonna lash out at me again! Explain to her again: "*Your tea is on the dining room table.*" (sighs) And then throughout the day she was very difficult. For everything we said and did wasn't good enough. She argued every point. That was Saturday. Sunday, the same story. I was stressed the whole weekend with Sue!

As with Linda, Patricia anticipated future episodes of aggression or acting out. The anticipation of such behaviours not only maintained her parental stress, it kept her on guard. The excerpt below describes Patricia's constant vigilance:

Patricia: And we can't just . . . I can't switch off. Sometimes Peter can switch off and not hear. But I can't switch off to Sue; I hear her all the time!

As with Linda and Patricia, Jeanette described apprehension and worry about the possibility of behavioural outbursts at numerous intervals during psychotherapy. Jeanette's parental stress revolved around the possibility that she might find Cindy and her husband arguing when she got back from work. At such times Cindy often became verbally and physically aggressive:

Original dialogue in Afrikaans

Jeanette: Want as ek aankom na die huis toe dan dink in my gedagte. . . ek hoop nie ek gaan nou weer 'n negatiewe iets hoor nie.

OC: Van mense wat praat oor Cindy?

Jeanette: Nee, veral van haar pa, of van haar.

OC [kruispraat] Ja!

Jeanette: Ek hoop in my hart dinge gaan reg wees.

OC: Ja-ja. Sê vir my hm-mm . . . as dit nou by ** [man se naam] se manier van Cindy hanteer . . . vertel vir my meer.

Jeanette: Hy het nogal rustig geraak na die polisie, maar soms tyd soos gister . . .

OC [kruispraat] Mm.

Jeanette: Gister wat hy nou sien sy hou aan en al die . . . toe sê (haar man):
“Die kind is mal, die kind makeer nog ‘n klomp pille”.

OC: Ja.

Jeanette: *“Hulle moet die pille meer maak”.*

OC: Ja.

Jeanette: Toe sê sy-sy wens daai man gaan dood.

English translation

Jeanette: Because when I am arriving at home I think in my mind. . . I hope I will not hear again . . . a negative something.

OC: About people that are talking about Cindy?

Jeanette: No, especially about her father or about her.

OC [cross talk]: Ja!

Jeanette: I hope in my heart that things would be all right.

OC: Yes, yes. Tell me, hm-mm. . . when it comes to ** [husband's name]'s way of managing Cindy's behaviour. . . Tell me a bit more?

Jeanette: He has become sort of relaxed since the police, but at times like yesterday. . .

OC: Mm.

Jeanette: Yesterday what he saw now (was) she kept going at it and all the. . . then (her husband) says: *"The child is crazy, the child needs a stack of pills."*

OC: Ja.

Jeanette: *"They must make the pills more."*

OC: Ja.

Jeanette: Then she said she wished that the man will die.

It is noticeable that Jeanette included a side-reference to calling in the police as a drastic measure of trying to de-escalate the conflict between Cindy and her father. Her stressful anticipation and constant worrying about finding her loved ones in conflict were constant themes throughout the sessions.

As described in the narratives, Sarah also experienced higher levels of parental stress and fear following episodes of Ethan's aggression and oppositional acting out behaviours:

Sarah: . . . so he went to go sit, he ate it up, and then ** [youngest daughter's name] came down, and ** [youngest daughter's name] said to me: *"Mommy, that is for us to take with us."* So I said: *"Don't you also start,*

because Ethan is also in a bad mood.” So he was sitting there, and that was the first time, I’m telling you, I was so scared, I started crying. Ethan just jumped up...

OC: [interjection] Hm

Sarah: . . . he was sitting, he finished what he was eating, he just jumped up and he took me by the throat . . . and he banged my head against the front door twice, twice or three times, can’t even remember. And then, it was so frightening, and then ** [youngest daughter’s name] came to my assistance and he took ** [youngest daughter’s name] also on.

Similar to the other parents, Sarah constantly monitored Ethan’s behaviour to assess risk. In the foregoing excerpt, Sarah’s description of Ethan’s “bad mood” meant she was apprehensive about the possibility of aggression.

One of Hadil’s descriptions resonates with some of our other conversations in therapy. It is a stark reminder of how disruptive, potentially embarrassing and distressing Ashraf’s behaviour could be, not only the outbursts of aggression, but also the need to phone the police to help her family with her son’s aggression and threats:

Hadil [cross talk] Exactly! Ja. I mean, not for nothing! If . . . if there’s an episode at home like he just wants to hit everybody or where he takes a knife or he takes a hammer and-and-and he wants to jump out of the window . . .

OC: Ja.

Hadil: And then I get . . . I can never bring him here on my own.

OC: Ja, ja.

Hadil: I have to phone the police! And . . .

OC: It's difficult!

Hadil: It's difficult and you know how the neighbours all come out to see what's happening? Why is the police here? And I. . . I've tried on many occasion(s) to say: "*Ashraf, please calm down and then we will . . . I will take you to the . . . to hospital like.*" But it never comes to that! Never . . . whatever he finds he will throw.

Marlene was the only participant whose parental stress was not directly attributed to the behavioural difficulties of her disabled child. As described in the narratives, Marlene attributed her parental stress mostly to her conflict with her son, Leon.

Thematic analysis suggested that Linda, Hadil and Jeanette started to focus less on their children's behaviour towards the end of psychotherapy. While aggression and other behavioural difficulties were initially described as the main reason why they had experienced parental stress, as therapy progressed other stressful life events and family constraints were explored in more detail.

Hadil increasingly focused on her compounded caregiving responsibilities and the perceived lack of family support. Jeanette continued to describe her child's obsessional behaviour and conflict with her husband as stressful, but she also increasingly disclosed her conflict with her husband and other concerns about his substance abuse. Linda and I co-constructed the meaning of earlier parental experiences and the loss of a healthy child. Linda also started to increasingly link

her stress with her husband's drinking and her conflictual relationship with her youngest child.

I read the transcripts repeatedly to understand why our focus had shifted; this phenomenon was also discussed in peer supervision. From their post-therapy interviews, Linda, Hadil and Jeanette highlighted the usefulness of psychotherapy as a means to *learn* more about their children and themselves. As described in the narratives, we paid considerable attention to psychoeducation on a basic level. It is possible that these three participants started to increasingly acknowledge other family and personal stressors that contributed to their psychological distress.

I am careful not to claim that the distressed reactions of mothers to their child's behavioural outbursts lessened as a result of the therapy. Rather, the three participants started to consider the influence of other caregiving and family stressors that were not directly linked with the child's behaviour. However, these three parents continued to respond with heightened parental stress when their children displayed aggression or other significant behavioural difficulties.

By identifying and focusing on her relationship with Leon, it could be argued that Marlene had already recognised the complexity of multiple, interactive social and family factors that maintained her parental stress. She told me she had family support to assist her with caregiving when Karin had manic episodes and subsequent increased irritability and aggression. Marlene also reported that she allowed Karin to continue with specific behaviours when she was manic, e.g., unpacking cupboards and restlessness at night. Marlene stated she knew that her child's behaviour would improve when mania subsided; and that she had strategies in place to deal with her daughter's behaviour.

Whereas Linda, Hadil and Jeanette made progress in their attempts to explore different contextual factors that were related to heightened levels of parental stress, Patricia and Sarah were less amenable to therapeutic initiatives aimed at facilitating this process. Until the end of therapy, these two parents maintained that their psychological distress were almost exclusively caused and maintained by their children's problem behaviours.

4.2.3 Other cognitive factors that were linked with parental stress

I cited examples of elevated parental stress in the face of the child's behavioural difficulties in the previous section: five of the participating parents reported increased stress if they had either witnessed or anticipated the onset of behavioural difficulties. I will now move on to discuss other cognitive variables that were associated with parental stress.

Anticipation and apprehension about possible behavioural outbursts often represented evaluative appraisals of the child's behaviour as a potential threat. I will now briefly discuss the most prominent maternal beliefs about their children's behaviour and their own elevated levels of parental stress:

4.2.3.1 Low self-efficacy and maternal helplessness about the child's perceived uncontrollable behaviour

Most of the participants reported perceptions of maternal helplessness to manage their children's aggression alongside expressions of parental stress. In five case studies, psychometric assessment on baseline measured low levels of parental competence comprising low parental satisfaction and low self-efficacy. Self-efficacy is conceptually described as a coping resource that is employed when coping strategies are selected (Folkman, 1984; Kelso et al., 2005).

Patricia's frantic efforts to "*keep the peace*" was based on perceptions that she lacked the coping resources to manage Sue's behaviour: Her beliefs were at times accompanied by automatic images of her husband going into cardiac arrest while he was trying to manage her daughter's behaviour. At its most basic level, at the onset of therapy Patricia believed that she had little control and success to manage Sue's behaviour; and she had little recourse to change the status quo:

Patricia: But it's a day to day process that, uh, I have to deal with, that I'm not coping with at all, but I'm doing it, because I have no other choice. I don't know . . .

OC: [cross talk] Mm.

Patricia: I don't have any other choice at this stage!

OC: Ja, ja.

Patricia: To do anything else; I don't know how to do anything else.

At the onset of therapy, Linda also believed that she had limited control over Tony's behaviour; her child's uncontrolled seizures led to perceptions of helplessness and an external locus of parental control. Linda believed that she lacked the agency and coping resources to deal with Tony's behaviour:

OC: Tell me, Linda, so you feel hopeless about the future. Do you also feel helpless about changing things?

Linda: Ja, because I don't know what to do or how to change things!

OC: Mm.

Linda: It is (that?) I don't have any resources or any assistance. How can you change a thing? I just wish it will go away! I could go to bed, wake up in the morning, everything is either normal or that I'm not there.

At the interview before therapy commenced, Hadil's response to my open and close-ended questions about coping with her child's behaviour elicited generalised beliefs regarding helplessness and the sense that she was overwhelmed by her compounded caregiving responsibilities:

OC: Ja. Is there anything you do when Ashraf gets ill and you get stressed that make you feel better, Hadil? Is there anything that works?

Hadil: Uh, no.

OC: It's terrible!

Hadil: There isn't an up there!

OC: Mm. Ja.

Hadil: There isn't! I won't know what to do.

OC: And what is the most difficult of your caregiving tasks? I mean, what do you experience as the most difficult?

Hadil: You know, I think . . . I don't know, maybe I'm just being . . . I think everything!

OC: Mm. Mm. Mm.

Hadil: There isn't anything I can say is not difficult.

Sarah also repeatedly described helplessness and a sense that she cannot manage Ethan's behaviour, with resultant elevations in parental stress. She continued to believe that she must give in to Ethan's demands to keep him from becoming aggressive:

Sarah: It . . . it, like I said, it all depends on Ethan, but . . . uh-uhm . . . if . . . I must just go the way Ethan wants to go, which means then (children yelling in the background) we okay.

At times Sarah accused Ethan of deliberately and purposively acting out in order to obtain food or snacks from her. At other times she described him as having little control over his behaviour, which she then vaguely linked with symptoms of an undefined psychiatric illness. In such instances Sarah insisted that his medication should be changed because *"it was not working"*. Sarah's assumptions implied an externalised locus of control.

Against the helplessness and uncontrollability that these four parents reported, Marlene told me repeatedly that she knew how to manage her daughter's behaviour following relapse into mania. As a professional nurse Marlene made sure that Karin was compliant to medication; she reported considerable family support; and she managed her child's aggression by following low arousal principles.

4.2.3.2 Maternal beliefs about diagnostic overshadowing, the intentionality of the child's behaviour and the role of psychiatric symptoms to explain behavioural difficulties

The external locus of parental control to manage their children's aggression could be explained by other parental perceptions and beliefs. Thematic analysis suggested that parents also held affiliated beliefs that their children were either intentionally acting out by being aggressive or oppositional. Alternatively, behavioural outbursts were explained by the child's intellectual disability and medical or psychiatric symptoms. The abovementioned attributions imply an external locus of parental control, i.e., that the child's behaviour was predominantly caused by internal triggers.

Jeanette largely attributed Cindy's behavioural problems to her child's ID and (contested) diagnosis of bipolar affective disorder. In fact, she believed that her daughter's obsessional behaviour was caused by the encompassing effect of "*Bipolar*". However, she was unable to describe how her daughter's diagnosis led to repetitive behaviours and compulsive phoning. As a result, Jeanette believed that she had little agency to exert control over her child's perceived biologically-driven behaviour; and she also described her efforts to manage her daughter's behaviour as being relatively unsuccessful.

Patricia stated throughout intervention that she knew Sue's behaviour was made worse by her psychosis and post-ictal aggression. Yet she also believed that Sue often acted out when she "*did not get her way*", which implied some degree of intentionality behind her daughter's behaviour:

Patricia: And also . . . it's because we did what she wants us to do. Not that it's [inaudible segment], it's going to gonna be not good for her health or it's

gonna hurt her, we did to keep her happy. (Long silence). But she wanted to do (clear throat) . . . Pardon, she wanted (clears throat), sorry, the usual braai (barbeque); go out to the Spur (a restaurant). As much as we didn't feel like it we did it.

Linda viewed Tony's oppositional behaviour and aggression as the result of psychiatric disorder and her child's ID. However, Linda confused psychosis with ID. When describing psychosis, Linda would often allude to her child's compromised information-processing deficits and perceived inability to self-regulate. I thought at the time that Linda underestimated her daughter's resilience and level of intellectual and adaptive ability.

Yet Linda also repeatedly stated that Tony knew *exactly* what she was doing. As I described in the narratives, she went to the point where she brought me a printout of some popular (and definitely not mainstream) article that sensationally claimed that epilepsy was the result of pathological attention-seeking. I surmised that Linda held conflicting views of her daughter's behaviour: on the one hand, Tony must have had considerable insight into her behaviour to allow manipulative tactics. On the other hand, Linda believed her child had limited social insight because of her intellectual disability-psychosis-epilepsy issues:

Linda: And then, of course, when she realises: okay, this is the way to treat you to get what I want, she keeps on doing it. She doesn't accept no for an answer!

In the same way, I recalled Hadil's agitated and intensive interrogation of her son's motives when we consulted the psychiatrist amid signs of florid psychosis. Hadil wanted to know whether Ashraf was trying to deliberately hurt her or question her

authority as parent through his behaviour. She appeared genuinely perplexed by her son's behaviour. She also repeatedly voiced her perceived inability to manage Ashraf's aggression, especially during the earlier parts of therapy, by noting that she *"did not know what to do when he got like this."*

4.2.4 Conclusion

This study has described prominent maternal beliefs about the child's behaviour. In turn, these beliefs led to elevated levels of parental stress. These findings are in keeping with a growing body of research that has highlighted the role of cognitive variables in parental stress among mothers of children and adults who have ID (Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; Dunn et al., 2001; Hassall et al., 2005; Hastings, 2002; C. Hill & Rose, 2009; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Neely-Barnes & Dia, 2008; Woodman & Hauser-Cram, 2013; Woolfson et al., 2010).

At a minimum, the findings from the present study suggest that participating mothers had stressful caregiving demands that were in part attributed to the behavioural difficulties of their children.

Whereas psychotherapy appeared reasonably effective in reducing depressive symptoms in four of the cases, comparatively fewer participants benefited from initiatives to lower high levels of parental stress. The findings of this study in terms of the use of psychotherapy to attempt the reduction of parental stress will now be considered.

4.2.4.1 The use of CBT and the clinical implications of findings

i) Introduction

While Linda, Jeanette and Marlene had reported significantly lower levels of parenting stress at post-assessment and 4-month follow-up, Hadil was unable to sustain lower levels of parental stress at follow-up. Jeanette did not complete her psychotherapy, however my observations of her improved psychological well-being were based on her feedback during the post-therapy interview and the subjective symptom checks that were conducted at the onset of each psychotherapy session.

Psychotherapy also failed to translate into tangible benefits to Patricia and Sarah.

Discussion will focus on the different outcomes of the six case studies.

ii) The use of CBT to bolster some of the coping resources that are required to lower parental stress, reduce blaming attributions and enhance an internal locus of control

It is conceivable that depressive symptoms compromised the coping resources of participants to deal with parental stress. Folkman (1984) argued that coping resources include:

- A person's specific beliefs about the nature of distressing events.
- Low levels of energy to respond to stressful events.
- Inadequate or ineffective problem-solving skills.

Four of the participants were able to more effectively use available coping resources once the negative impact of depressive symptoms are attenuated or resolved. They were subsequently able to employ different coping strategies which in turn led to lower levels of parental stress.

All six of the participants presented with appraisals that they lacked the skills and resources to effectively manage their children's behaviour. In light of the severity of the children's behavioural difficulties, often on top of medical or psychiatric diagnoses, maternal perceptions of helplessness and inadequacy were to an extent valid.

Nevertheless, as an umbrella term, not *all* the behavioural problems were *completely* unmanageable *all* the time. At different intervals, cognitive distortions prevented parents from using their agency and resources to manage their children's admittedly complex behaviours.

Psychotherapy accordingly paid close attention to negative automatic thoughts that were based on core beliefs of helplessness and parental inadequacy. As part of a collaborative working relationship, I did my best to unpack, explore and refute distortive thoughts about the child's behaviour.

On a behavioural level, we covered rehearsal exercises, skills training and problem-solving methods to deal with distressing caregiving demands that included the child's aggression and other behavioural difficulties. In order to mitigate ideas about catastrophic outcomes and perceptions that "*nothing works*", we also tried to enhance appropriate assertiveness against other family members and their children who have ID.

Marlene realised that she had agency to assert herself against Leon's accusations; and Linda took initiative to seek formal medical support for Tony's behaviour by going through the district health system for the first time. Hadil attended a wedding in another city without her husband and sons, something she had not done before;

and Jeanette stood her ground in disallowing Cindy from making repeated phone calls.

Some of the participants reported they felt somewhat less helpless after they had realised that there were other recourses to manage distressing caregiving events and family conflict. It is conceivable that Hadil, Linda, Jeanette and Marlene were able to reappraise distressing caregiving events as less unmanageable after they had bolstered their available coping resources through different initiatives.

Psychoeducation and cognitive restructuring focused on the beliefs that maintained elevated parental stress, helplessness, inadequacy and non-assertiveness. For example, Linda and Hadil developed an understanding of their children's psychosis as the result of neurobiological mechanisms *and* complex ecological variables. Their perceptions of problem behaviours as intentional and deliberate displays of acting out shifted after psychoeducation had facilitated a degree of reattribution.

Marlene and Linda made similar gains with regard to parental locus of control. Based on the results of psychometric assessment, clinical observations and post-psychotherapy interviews, I believe that a more informed understanding of their children's pathology also improved their internal locus of control and overall parental satisfaction. Conversely, Hadil's post-assessment scores on the Parental Locus of Control Scale (PLOC) and Parenting Sense of Competence Scale (PSOC) underscored clinical observations to suggest that she continued to externalise her locus of control.

During the last session Hadil increasingly referred to Ashraf's psychosis to account for his odd beliefs and bizarre behaviours. This stood in stark contrast to her earlier expressions of distress, anger and frustration because of Ashraf's reported

intentional acting out behaviours. For example, following psychoeducation about the negative symptoms of schizophrenia Hadil no longer believed that Ashraf was deliberately trying to spite her by not washing.

It is interesting to note that many of the participants were also distressed about their relationships with other family members, i.e., their children who did not have intellectual disability. Although this is solely based on clinical observation and not confirmed by Marlene, I got the impression that her anger towards Leon subsided as she became more assertive towards him. As described in the narratives of Linda's sessions, Linda stated that her relationship with Kim improved after she had gained new insight into the reasons why her youngest child was oppositional and rebellious.

Without claiming to proportionate the effect of psychotherapy, maybe two quotes from Linda during our post-psychotherapy interview will elucidate some of her therapeutic gains:

Excerpt 1:

Linda: It was very, uhm, enlightening. I came here very despondent and didn't see any way forward, but during all these interviews [sic: therapy] you made me realise that it's . . . nothing . . . of this is because of my doing; uhm, it made me see things in another light; I'm better equipped. . . . And hopefully in the future I will be able to handle and understand her better! (Tremor in voice).

Excerpt 2:

Linda: Yes! I am not a bad mother. Uhm . . . (pause) I'm not that helpless or hopeless anymore . . . from what I used to be. Uhm . . . at least I can . . . I can make a . . . a decision without interference of anybody else or have the help of

anybody else. I am firmer with Kim where I used to just let it go. Do your own thing to avoid problems. But I've grown!

Unlike Marlene and Linda, Hadil was unable to sustain lower levels of parental stress at 4-month follow-up. As described in the narratives, there were different contextual factors that should be considered as part of the reasons why Hadil's parental stress increased following the gains she had made in therapy. Yet she told me that therapy inculcated new ideas about caregiving and coping; and that she learnt a lot. As confirmed by clinical observation and a BDI-II score of 4, Hadil's mood remained euthymic even though she was highly stressed following all the adverse events that she encountered.

iii) Patricia and Sarah: Therapeutic failure to alleviate parental stress

Against the gains that Linda, Marlene and Jeanette had made during psychotherapy, it is equally important to seek answers about the reasons Patricia and Sarah did not experience significant reductions in parental stress:

First, it is possible that the therapeutic relationship between therapist and client lacked rapport and the required collaboration to realise therapy goals. Our sessions were at times stilted and I was concerned about the quality of my therapeutic alliance, especially with Sarah.

Second, social context and family dynamics must be considered: Patricia's complaints about her husband and children's inappropriate or inadequate support resonate with Sarah's complaints of not being supported by her children. Of course, as I will describe in the next section, other participants also experienced significant tension with members of their nuclear families. I did not conceptualise family

variables as insurmountable obstacles that prevented Sarah and Patricia from benefiting from psychotherapeutic input. Instead, confirmation of support from Sarah's youngest daughter and Patricia's husband led me to conclude that inadequate family support might have been at best contributing factors to their poor response to therapy. It is therefore more likely that other personal factors in the therapist-client relationship might at least partly explain the disappointing outcomes.

Third, prominent traits of pervasive developmental disorder in Sarah's presentation lowered her amenability to psychotherapy and impinged upon the formation of a strong, collaborative relationship between us. It should also be noted that Patricia's mood and parental stress improved markedly following the prescription of antidepressant medication after therapy had been completed. It is possible that the severity of her depression and anxiety lowered her amenability to psychotherapy (Wright et al., 2006).

Last, Patricia and Sarah firmly believed that group home placement of their children afforded the most viable and sustainable solution to their caregiving problems. After being asked to come up with as many ideas as possible of how to manage Ethan's behaviour, Sarah told me the following week that she had come up with a plan to address her distress and manage Ethan's behaviour: he was to be placed in a group home at the earliest available opportunity.

Patricia had similar views of placement as the final solution. As described, Sarah lost some interest in seeking other solutions once a set of rather unwavering suppositions of group home placement as *"the only option"* had taken form.

iv) The use of CBT to change existing coping strategies when dealing with parental stress

The Ways of Coping Questionnaire measured maternal coping strategies at various intervals of the intervention process in each case study. Parents were asked to recall a recent distressing caregiving event involving their children.

Thematic analysis failed to reveal strong patterns of coping across the different cases and the collective use of preferred strategies was not evident. However, when looking at each case study on an individual level, an interesting pattern emerged: the individual participants changed their coping strategies quantitatively or qualitatively as therapy progressed.

At first, I was confounded by the different responses from parents. Individual responses tended to overlap with the person's progress in therapy (or lack thereof). One or two examples will illustrate how Ways of Coping responses reflected individual processes more than emerging similarities across cases:

As therapy progressed, Patricia's started to employ a wider array of coping strategies to deal with Sue's behavioural difficulties. She made a concerted effort to manage her child's behaviour more effectively. However, efforts to deal with stressful situations and a corresponding increase in strategies do not automatically translate into reduced psychological distress (Folkman, 1984; Woodman & Hauser-Cram, 2013). As described in the narratives, she tried to implement low arousal approaches and other problem-solving techniques to deal more effectively with Sue's behaviour. Patricia also attempted to decatastrophise Sue's outbursts. Her scores on the Ways of Coping Questionnaire doubled from baseline to post-intervention

assessment. However, the fact that she tried different coping strategies did not translate into lower levels of parental stress or clinical depression.

Ways of Coping responses suggest that Marlene and Linda had progressively used a small number of coping strategies less frequently to manage their children's behavioural problems. Whereas both made frequent use of mental disengagement and escape-avoidance, Linda responded to therapy by increasing her efforts to confront difficult issues regarding the management of Tony's behaviour. For the first time she admitted Tony through the district hospital system; figuratively, she also embarked on a painful journey to explore unresolved issues regarding her earlier experiences of the loss of a healthy, normally developing child. This implied some element of risk-taking against the status quo of denial and repression. As a result, Ways responses reflected progressive elevations in Confrontive Coping and significant reductions in Accepting Responsibility and (emotional) Self-Controlling.

Against Linda's use of greater risk-taking and willingness to confront painful memories, Marlene became less confrontational in her attempts to manage distressing caregiving situations. She also spent less time in her room when she felt overwhelmed by caregiving tasks or when avoiding conflict. Linda continued to display prominent escape behaviour when Tony acted out.

I was initially disappointed that the Ways of Coping Questionnaire did not show an inverse relationship between problem-solving and parental stress. The across-case analysis failed to show consistent reductions in the use of escape-avoidance and stratified increases in the employment of problem-solving. As highlighted in the literature review, the less frequent use of the former and application of the latter have been correlated with reduced levels of parental stress among mothers of children

who have developmental disability (Dunn et al., 2001; Glidden et al., 2006; Kim et al., 2003; Paster et al., 2009; Seltzer et al., 1995; Woodman & Hauser-Cram, 2013).

It was nevertheless meaningful that the participants changed their coping strategies during therapy. In a very real sense, the different responses of participating mothers reflected the complexity and subtle shifts in a process that allowed the in-depth exploration of the maternal experiences that they disclosed in therapy.

4.3 Parental Stress and Maternal Depressive Symptoms in the Context of Other Health Issues and Stressful Social Factors

4.3.1 Introduction

The themes that emerged from analysis were in general negative and pessimistic. All the participants reported a pile-up of adverse caregiving events that had left them with a sense of hopelessness about the future prospects for themselves and their children.

I was again reminded that the participating mothers represented the extreme end of parents of adults who have ID: the children of this study's participants presented with severe behavioural problems; and the experience of sustained elevations of parental stress was an inherent selection requirement of research.

Besides the reports of negative emotions and behaviours, mothers also reported a small number of positive experiences. Marlene highlighted the love and compassion that she felt towards Karin; Hadil made sense of her adverse experiences through faith and religious meaning; and Jeanette repeatedly referred to the close bond of affection she felt towards Cindy.

As described in the literature review, an expanding body of research has investigated positive caregiving experiences among mothers and fathers of children who have ID. Research has found that parents of adults who have ID experienced existential growth, companionship and practical support in many of their activities of daily living. These gains were directly attributed to caregiving and the positive impact that their children had on their lives (e.g., Blacher et al., 2013; Griffith & Hastings, 2013; Hastings & Taunt, 2002).

However, against the constant negative notions of stress, depressive symptoms, shame and anger, positive rhetoric constituted at best only a negligible part of the thematic content.

A recent qualitative study has described similar parental experiences of negativity, hardship and emotional distress (Faust & Scior, 2008). It is important to note that their study has explored caregiving experiences among parents of children who have ID *and* mental health problems. The authors made a valid point that resonated with the findings from the present study:

The central question in evaluating the present findings is to what extent the experiences described by parents in this study differ from those parents whose offspring have intellectual disabilities alone, and from those whose offspring experience mental health problems in the absence of intellectual disabilities.

(Faust & Scior, 2008, p. 422.)

The reader will recall that Patricia, Linda and Sarah attributed all their psychological distress to their children's behavioural difficulties and other caregiving demands. These three participants also held negative perceptions about other distressing life

events without seemingly recognising that such expostulations were inherently in conflict with their global attributions that described their children as the only stressors in their lives.

The children of this study's participants had an array of mental health and medical problems that included schizophrenia, post-ictal psychosis, mania, autism and anxiety disorder.

The themes that emerged from analysis contested linear and reductionist views of parental stress and maternal depression as the undisputed and predictable end products of the child's behavioural difficulties and psychiatric illness.

Likewise, the cognitive variables of parents did not fully explain their distress and depressive symptoms.

Thematic analysis and clinical observations produced findings that contested Linda, Patricia and Sarah's assertions that their caregiving tasks and children's behaviour were responsible for all their psychological stress. Each case study made it clear that the caregiving capacity of parents and their well-being were inseparable from broader indices of their physical and psychological well-being. In addition, different socio-economic and familial factors were identified as distal factors to maternal distress and depressive symptoms. These findings will now be described in more detail.

4.3.2 Maternal mental health and the formative influences that shaped contemporary beliefs

The first two sessions with participants were used to conduct comprehensive psychological assessment in accordance to the principles of CBT. Assessment included questions to obtain applicable personal background information and assess for possible psychiatric problems. The role of social and economic factors on the person's psychological well-being was also explored during the first sessions (J. Beck, 1995).

The World Health Organization defines mental health problems as:

. . . a broad range of problems, with different symptoms. However, they are generally characterized by some combination of abnormal thoughts, emotions, behaviour and relationships with others. Examples are schizophrenia, depression, mental retardation and disorders due to drug abuse. (World Health Organization, n.d.)

As a registered clinical psychologist, my training in psychopathology enabled me to observe and interpret specific patterns of maladaptive behaviour, distortive cognitive processes and emotional dysregulation that were linked with mental ill-health. In addition, CBT requires a case conceptualisation that would inform treatment planning; and the role of psychiatric disorder in maintaining subjective distress is acknowledged in CBT conceptualisations (e.g., Wright et al., 2006).

When applicable, I also discussed the vicissitudes of the diagnostic process in peer supervision to allow ongoing reflexivity and a rigorous and respectful conceptualisation of the participant's presenting problems. I openly discussed positive and negative countertransference feelings and the potential value this had

as a means to inform treatment. By listening to some of the audio-recordings and the interrogation of written transcripts, the other psychologist observed the same psychological problems in the presentations of Patricia, Linda, Hadil, Marlene and Sarah. The one point of divergence pertained to possible symptoms of post-traumatic stress besides features of generalised anxiety in Patricia's profile. After considerable attention to this matter I eventually decided that Patricia's fear, anticipation and avoidance were better accounted for by symptoms of generalised anxiety.

The participating mothers actively engaged with the questions regarding mental health issues. We were therefore able to collaboratively co-construct many of their psychological problems during discussion.

As described earlier in the section, five of the participating mothers presented with depressive symptoms and other mental health problems. In the context of the study's focus on parental stress and the emerging clinical material from the first cases, I wanted to find out more about the following:

- Did parental stressors, i.e., those that had led to escalated parental stress, also precipitated and maintained most of the depressive symptoms? If not, what other stressful events precipitated and maintained maternal depressive symptoms?
- In a similar way, did other mental health problems cause psychological distress? How would parental stress then be understood when the signifiers of stress were possibly grounded in broader aetiological and maintaining processes within the mother's life?

- Were there other mental-health problems that depleted coping resources and moulded many of the coping strategies that parents employed to deal with parental stress and distressing caregiving experiences?

The thematic analysis of therapy sessions strongly suggested that maternal depression or dysthymia was the result of a combination of life events that included, but was not restricted to, adverse caregiving experiences. Moreover, as described in the narratives of sessions, each parent presented with unique personal histories, social circumstances and psychological profiles that included different mental health problems and broader life events that were at times outside the parameters of parenting a child who has a disability:

Patricia told me that she had always been an anxious and nervous person. She linked her parents' substance dependence and her father's unpredictable temper as the reason why she continued to experience anxiety and nervousness:

Patricia: I'm just a nervous person from the word go.

OC: Mm. Mm.

Patricia: And now... ja.

OC: It's been like that your whole life?

Patricia: All my life.

OC: Yeah?

Patricia: All my life. I was a nervous wreck before I even got married because of my upbringing. So it stayed with me.

OC: A very strict father?

Patricia: Ohhh! Hitler.

Patricia described early childhood experiences of helplessness and desolation because of her parents' substance dependence. Marlene grew up in absolute poverty and was teased at school because they were so poor. She recalled in therapy how helpless this had made her feel; she also reported her attempts to put on a show of bravery to combat perceptions of her inferiority and low self-esteem at the time.

Marlene's experience of IPV saw its onset before her children were born. She was treated and hospitalised for clinical depression as a result of her marital problems and the abuse that took place at the time.

Linda lost her grandfather when he was murdered. She recalled that she felt estranged and disconnected from her family throughout her childhood. In the excerpt below Linda spontaneously related how her early childhood experience of feeling disconnected from a family with little expressed emotion had a bearing on her present difficulty in showing affection towards her children:

Linda: But, the day you-you grow older and you get married, then the bond between you and your mother . . . Uhm, my mom grew up as well in a household where my granny didn't show any affection. So I don't know if it's just because I was a girl as well that she couldn't show affection to me as well. I loved my kids to bits when they were small, but up to a certain age, then I also . . . It feels like I dis-distanced myself from them.

4.3.3 Family tension, financial hardship and inadequate or inappropriate family support

The participating mothers often reported depressive symptoms such as increased sadness following life events that were not directly linked with their caregiving roles as parents of adults who have ID. As described in the narratives across different cases, such events and relationships included persistent family conflict, the conduct and behaviour of their other children, marital acrimony, chronic medical conditions, IPV and in Hadil's case, violent crime.

Sarah reported feelings of bitterness and frustration about her children's avoidant behaviour and apparent lack of interest in their mother:

Excerpt 1:

Sarah: [interjection] But then . . . uhm . . . my children they don't look out for me, so I don't see why I must give them money . . .

Excerpt 2:

OC: Okay, okay. Sarah, thank you for that. Uhm . . . it feels like you . . . you feel quite hurt when your children are not really phoning you or . . .

Sarah: [interjection] Ja, because, uhm . . .

OC: [cross talk] . . . sms'ing you?

Sarah: . . . they . . . uh-uhm . . . (shuffling) they only come see me when they need money from me. . . When they need something, an' . . . I'm not falling for it anymore!

As illustrated in the narratives, conflict and other forms of tension between family members were often reported as being stressful. While the child who had ID was sometimes implicated in family discord, this was by no means always the case. The following excerpts are examples of stressful family incidents and events across all the cases. Thematic analysis identified family conflict and stressful family events as a prominent theme:

Patricia gave maximum ratings to feelings of guilt and sadness after she had observed possible signs that her son had started using marijuana again. She also reported feelings of distress because her children spent so much time at home. While not actively implying conflict, Patricia told me she had little time for herself:

Patricia: I just don't need my family, my children to be so involved in my life.

OC: Overinvolved?

Patricia: Overinvolved! There're always there. ** [other daughter's name] and her fiancé are there every day. . . And I don't need that. We've had lots of issues about this before, and, uhm, I need my space! (Pause) And to some people it doesn't sound nice . . .

As described in the narratives, Linda confirmed conflictual relationships with Kim and her husband at various times of intervention. The following excerpt provides an example of conflict with Kim:

OC: (laughs) So, Linda, what got to you most about the incident? What hurt you most?

Linda: The swearing, uhm . . . Calling me useless, uhm . . . She doesn't want to stay there anymore; she's gonna move out and stay with Rita. Uhm, just the hurtful things she said.

OC: Mm. Mm.

Linda: I ignored her for the rest of the evening and the next day, but then she came crying and said ja, she's sorry, she's sorry she didn't mean it that way, but she was angry and she can live without Tony, but she can't live without me. But I said it's too late!

As described, Hadil reported an acrimonious relationship with her eldest son:

Excerpt 1:

Hadil: Yusuf has issues; he's now three weeks . . . three weeks since that other episode with his friend, he doesn't talk to me.

Excerpt 2:

Hadil: He's a very bitter child, hey?

OC: I can imagine.

Hadil: Very, very bitter. And with me.

Marlene's arguments with Leon pertained to disagreements about money and he blamed her for his exposure to trauma in early childhood. Their arguments were not primarily focused on Karin:

Marlene: And I got now a 28-year old (inaudible segment) where he, uhm, a gentleman, but me and him always argue.

OC: Mm.

Marlene: And sometimes, he sometimes says, he's telling me: "*Why is Mommy is going on?* [sic]" Like maybe, like: "*I'm not your son.*"

OC: Mm. Mm.

Marlene: We'll argue about small things. Don't ask me money if you don't work for money. You got a girlfriend, don't use my money for-for a girlfriend; you have to work and some things to make money.

Besides intimate partner violence, at the onset of psychotherapy Jeanette acknowledged that she was regularly in conflict with her husband, especially when he was intoxicated. She also said she often felt angry towards him:

Jeanette: [Stilte] Ek raak-ek raak party dae kwaad soos ek nou vir u sê.

OC: Mm.

Jeanette: Kwaad!

OC: Ja?

Jeanette: Ja. Maar dan vra ek vir die Here vir selfbeheersing, want Saterdag het ek gevoel ek wil, ek wil my man klap. Maar ek het net gedink ek gaan my hande seer maak (lag).

Translation into English:

Jeanette: [Silence] I get - I get angry some of the days like I have said to you now.

OC: Mm.

Jeanette: Angry!

OC: Ja?

Jeanette: Ja. But then I ask for God for self-control, because it felt on Saturday as if I wanted, I wanted to slap my husband. But I thought I would hurt my hands (laughs).

All the participants reported family conflict; and four of the participant mothers also described marital acrimony or tension. In addition, all six of the participants described their available family support as either insufficient, inappropriate or completely absent.

In Patricia's case, descriptions of her husband who always "*came running*" when Sue demanded food items left her with feelings of anger towards him.

Linda described her husband as "*my fourth child*"; she openly stated he does not support her in caregiving tasks or financially.

Hadil told me she felt too guilty to share the burden of care with her husband; and she stated her husband had withdrawn especially after her third son lost his vision. She reported that her feelings of guilt led her to approach her husband for a divorce, thereby "*freeing him*". I also described Hadil's distress about her brother-in-law's criticism towards her management of Ashraf's caregiving. As opposed to being supportive, his criticism had made her feel guilty, despondent, angry and upset.

Jeanette was able to leave Cindy with her husband when she went to work, but the constant bickering and conflict between father and daughter and her husband's substance abuse continue to worry her throughout the day. She became very sad when she told me her husband is "*onbevoeg*" (English = incompetent) to look after

Cindy; she also worried what would happen to Cindy if she passed away before her husband:

Jeanette: Sê nou ek sterf en Martin . . . Martin kan nog gered word, niks is onmoontlik nie, maar sê nou ek sterf gaan hulle nie vir Cindy in Martin se besit [sic] . . . Cindy sal nie by Martin kan bly nie!

In English:

Jeanette: Say I die and Martin. . . Martin could still be saved; nothing is impossible, but let's say I die and they will not place Cindy in husband's possession [sic] . . . Cindy will not be able to stay with Martin!

Jeanette also recalled that Social Services believed her husband was unable or incapable to provide care to Cindy. At a minimum, it appeared that her husband's support with reference to caregiving was compromised because of his substance dependence.

While Marlene told me that she received good family support from her extended family, she appraised her son's conflict with Karin as stressful because of his lack of understanding about Karin's psychiatric symptoms and behavioural problems:

Marlene: Karin is screaming like hell; Leon is screaming: (mimics son in high-pitched voice) . . . the two of them starting; and Leon can't . . . blah-blah . . .

And I'll want Leon to understand: *"But Karin is not you; Karin is a sick child! . . . why can't you understand?"*

Sarah was able to leave Ethan in the care of her eldest daughter, but at other times she repeatedly described her children's unwillingness to assist her with caregiving and support her.

The findings of inadequate family support and maternal isolation resonate with similar themes that emerged in a number of qualitative studies that have explored the phenomena of parental stress and caregiving burnout among mothers of children who have DD (Hayes & Watson, 2013; Kelso et al., 2005; Kenny & McGilloway, 2007; Wieland & Baker, 2010).

Apart from tension and conflict within their immediate family environment, all the participants of this study described broader socio-economic stressors. In fact, family arguments often revolved around socio-economic problems and hardship. Accordingly, socio-economic stressors had a negative impact on maternal mental health and the capacity of parents to deal with distressing caregiving events. Furthermore, maternal experiences of hardship were often associated with negative parental appraisals that the child's behaviour exceeded and taxed available utilitarian resources.

As described in the narratives, Sue acted out and Patricia felt stressed and angry after they had to spend money on restaurant food following Sue's unflattering remarks about her home-cooked meals; Linda had a heated discussion with her husband about the food he "*stole*" from the fridge; and Hadil felt guilty about Ashraf's unwillingness to eat vegetarian meals. The family's finances did not allow them to have meat-based meals each day of the week.

In fact, Ashraf's binge eating was one of Hadil's greatest stressors. Not only did Hadil worry about metabolic disease and Ashraf's expanding waistline, she also became angry, frustrated and worried that he was "*eating up our food*". She was worried that they would be left without food towards the end of the week.

Jeanette was highly distressed when the fridge broke, in part because they could not afford to replace the twenty-seven-year-old refrigerator. In our seven sessions, Jeanette described conflict with her husband about food on three occasions, including when he accused his other son by stating that his offspring was eating without contributing to the family finances. In addition, Jeanette repeatedly referred to the high cost of food and her constant worry to make ends meet.

Sarah's listing of food was documented in the narratives – she also made it explicit that Ethan's consumption of large quantities of snacks had a pervasively negative impact on her budget.

The participants of this study and their families did not experience absolute poverty; and all the families had access to a regular income from at least one family member.

None of the family members of participating mothers went hungry, and they all came from home-owning families. However, Jeanette and Sarah experienced relative poverty, while the income Linda earned was barely enough to meet the basic financial obligations of her youngest child's education and monthly expenses such as electricity, municipal services, petrol, etc.

Even as a qualified nurse, Marlene faced considerable financial headwinds after she had to use her retirement funds to secure her house.

The responses from most of the participants suggest that most of them were financially insecure. Hence, family conflict and the subsequent escalation of maternal stress resulted from appraisals that the continued security of their family was in jeopardy.

Of course, with various measuring scales and cut-off points, the definition and operationalisation of poverty have been contentious research topics in low-, middle- and high-income countries (Noble, Wright, & Cluver, 2006). While commercial research has employed socio-economic status as a measurement of the affluence-poverty continuum in South Africa, studies have employed various measurements to describe relative poverty (Higgs, 2007).

An in-depth exploration of poverty and the criticism against its operationalisation and measurement in South Africa go beyond the research agenda of the current study. In the context of the current study, all six mothers had reported recent incidents when their families did not have adequate funds to meet basic needs. The list of unaffordable items included meat, petrol, clothes, replacing broken windows, airtime, and a new refrigerator.

4.3.4 Maternal physical and mental health and other psychological problems that warranted clinical consideration

Four of the five depressed mothers were diagnosed with chronic physical conditions. The psychological impact and illness intrusiveness of all these conditions were linked with depression. Accordingly, research has established a positive connection between depression and lupus erythematosus (e.g., Palagini et al., 2013), diabetes mellitus (e.g., Karlsen et al., 2011; Shah et al., 2011), arthritis (e.g., Covic et al., 2012) and chronic obstructive pathway disease (e.g., Goodwin et al., 2012).

Again, a thorough investigation of the relationship between depressive symptoms and the specific chronic physical illnesses of different participants goes beyond the scope of the current study. It is important, however, to recognise that physical illness

may have played a contributing role in actualising depressive symptoms amongst the majority of participants.

Thematic analysis suggests that specific psychological problems among some of the participants had an influence on their emotional, behavioural and interpersonal responses to adverse caregiving events. With the exception of mood disorder, it is important to note that different participants presented with different psychological problems.

Barring depression, the focus of analysis was therefore not on the identification of overlapping mental health problems across different cases. Instead, I explored the negative impact of different psychological problems on the caregiving capacity and coping responses of the individual mothers. Adverse parental experiences also tended to exacerbate symptoms or traits of specific psychological problems among different participants.

Sarah's mild features of autism had a pervasive impact across different domains of parenting. As I described in the narratives of Sarah's therapy, traits of fundamental rigidity and inflexibility had a direct bearing on her parental practices.

Her amenability to therapy was lowered by the relatively poor quality of her social overtures and responses in conversation. On the level of cognitive processing, Sarah's problems with generalisation and filtering limited her insight into Ethan's autism-related problem behaviours. I believe that issues regarding social impairment also permeated other areas of her life, which left her vulnerable to possible abuse and exploitation.

Linda's presentation of borderline traits had an impact on her psychological well-being across various domains of her life. Episodes of frustration and anger were based on valid precipitating stressors at work and home, but there was evidence that the intense emotional processing of stressful events caused distress on intrapersonal and interpersonal levels. Linda became intensely dysphoric at various intervals of therapy. Such episodes were not only instigated by depressive schemas, but also when discussing topics that were based on fundamental beliefs of being unlovable or defective. Her decision to remain in a marriage notwithstanding unbearable circumstances was possibly related to a fear of abandonment, although there were also financial considerations to consider.

In hindsight, my conceptualisation and corresponding treatment plan of Patricia's presenting problems failed to adequately address symptoms of generalised anxiety. This could be another reason why Patricia did not make adequate progress in therapy. More specifically, even though her coping efforts doubled from a low baseline to post-assessment scores on the Ways of Coping Questionnaire, our narrow focus on parenting and the management of Sue's behaviour did little to ameliorate Patricia's high levels of free-flowing anxiety.

Patricia's descriptions of being "*a people's pleaser*" and a "*nervous wreck*" caused acute dissonance. She disclosed apprehensive expectations about routine tasks, family responsibilities and the possibility of unexpected events resulting in negative outcomes. She was constantly fearful of break-ins, motor vehicle accidents and the safety of her family. Towards the end of therapy, Patricia told me that she sometimes started worrying about upcoming social events more than a week before they were scheduled to take place. Everyday household tasks had to be completed before she was able to lower her nervousness.

Cognitive therapy did not focus on recognised strategies to alleviate generalised anxiety, e.g., uncertainty recognition and worry awareness training (e.g., Simos & Hoffman, 2013). While her constant apprehension about Sue's behavioural outbursts received attention in therapy, we did not focus on broader patterns of generalised anxiety.

Based on neuropsychological markers, there were clinical indications of mild neurological impairment in Marlene's profile following a minor stroke two years before she attended psychotherapy. Whether she conversed in Afrikaans or English, more comprehensive assessment was warranted because of the following: Her verbal fluency, coherence, focus, attention and concentration fluctuated from session to session. At times her line of thought was difficult to follow:

Marlene: We have our ups and downs but if . . . not once but three years ago . . . maybe . . . (inaudible segment) ** [brother's name] or whoever . . . So they, uhm, he was sitting** [brother's name], have something to drink; and sitting around the fire, talking about, uh, our childhood and things. Uhm, and then they were . . . they don't come . . . so I-I-I thought I was a trigger where they . . . okay just . . . the . . . they think they were doing something good, right? I must (inaudible segment); I must stop helping other people; stop giving her blah-blah-blah-blah! Is just because ?(I must go and help other people)? and they were just chopping me like hell! (making sounds with her hand against the sofa) And I didn't ask a thing.

4.3.4.1 Maternal anger

It was noticeable how often many of the participants became angry, frustrated, upset and annoyed whilst they were describing adverse caregiving events. Recollections of their children's behavioural difficulties or other caregiving responsibilities were frequently accompanied by marked mood shifts, physiological arousal and distinct changes in the pitch and tone of voice.

Patricia did not mince her words when describing her anger about Sue's demanding behaviour and the impact it had on her anxiety levels:

Patricia: So, you might say that he switch(ed) off, but he doesn't switch off and ignore her! He somehow doesn't get the way I get . . . I get completely stressed, anxious, angry . . . Very angry!

OC: Yes.

Patricia (sighs): There's times where, uh . . . There was some occasions where she gets so . . . I want to hit the head off her shoulders! The thought comes to my mind.

Jeanette was the only participant who did not regularly display emotions of anger, but at times she became annoyed when we discussed her relationship with her husband. Marlene's language was at times interspersed with highly emotive and offensive words and phrases that described her anger towards Leon and other family members.

Patricia, Linda, Hadil and Sarah directed their anger towards their children who have ID *and* other family members or acquaintances in their lives.

For example, Linda repeatedly described her feelings of anger towards her husband, which often resulted in acrimony and bitter accusations. I also described Linda's arguments with her youngest daughter. Linda was also frustrated, annoyed and angry with Tony, especially when she thought that her daughter was displaying manipulative behaviour. Sarah's conflict with Ethan and the use of physical punishment were covered in the narratives. When I asked Sarah during Session 7 why she lashed out at Ethan, she simply responded by saying *"because he was making me angry."* Hadil's relationship with her eldest son evoked feelings of anger and frustration; she was also upset about Ashraf's behaviour until she understood his psychiatric symptoms.

Thematic analysis suggests that Patricia, Linda, Hadil, Marlene and Sarah presented with dispositional anger. They also displayed state anger. In the context of the current study's focus on maternal caregiving experiences, state anger refers to anger that is caused or maintained by caregiving incidents or the behavioural difficulties of their children who have ID. As described in the literature review, trait or dispositional anger perpetuates the frequency and severity of state anger (Deffenbacher et al., 1996).

State anger was often evident when parents recalled distressing events that occurred in the earlier years of parenting. This related to especially Patricia, Linda, Hadil and Marlene.

The DSM V has linked anger with generalised anxiety, i.e., irritability that could result in anger; and the association between anger and borderline personality disorder is also well-established. Furthermore, the DSM V places anger modulation as a diagnostic classification of mood disorders (APA, 2013).

Thematic analysis suggests that dispositional anger was caused by different individual factors in each case study, for example Patricia's anger towards Sue was maintained by heightened levels of irritability that was more pronounced when she was more anxious. Many of Linda's responses to interpersonal conflict were also activated by stable traits of interpersonal engagement.

However, possible relationships between psychiatric symptoms, personality traits and maternal anger were less evident in the other case studies. Sarah's anger could not be directly accounted for by features of mild autism. It is conceivable, however, that a rigid manner of engagement might have had an indirect impact on her ability to problem-solve and cope effectively with her parental stress and Ethan's behaviour. In turn, as described in the narratives ineffective coping also at times resulted in frustration, annoyance and anger.

The five participants shared the status of being the primary caregivers of adults who have been part of their households for decades. In this context, the five participants had to manage their children's persistent behavioural difficulties for a prolonged period of time. Participants were also exposed to other stressful situations which tended to follow a similar longitudinal trajectory. Examples include Linda's marital acrimony and Hadil's compounded caregiving responsibilities.

While state anger was observed as contemporary reactions against distressing caregiving situations, the pile-up of adverse life events through the years also reinforced maternal anger. As described throughout this study, the consequences of ineffective coping included depressive symptoms. If anger was another negative emotion that resulted from persistent perceptions of helplessness and inadequacy, its manifestation might have become ingrained and dispositional.

My sense was that participating mothers grappled with difficult real life issues; and on many occasions their struggle to comprehend *what* was happening to themselves and their children left them with unresolved feelings of sadness, frustration, guilt, annoyance and anger.

In most instances, maternal reports evoked countertransference feelings of empathy: Hadil's anger about the treatment of Ashraf in the acute psychiatric unit felt valid; and Linda's embittered expostulations about her husband's behaviour was understandable. It also makes sense that the participating mothers got angry at their children because of strongly held (though often distorted) beliefs that their offspring were intentionally acting out. Of course, all these parents experienced high levels of stress, which has also been shown to be closely related to negative affect and anger (e.g., Arslan, 2010).

4.3.4.2 The use of CBT and clinical implications in the management of parental anger

One of the shortcomings of this study is the omission of a brief psychometric instrument to measure maternal anger. Psychometry was therefore not employed to gauge subjective ratings of anger at various intervals of the psychotherapy process. I observed that some of the participating mothers became less angry as therapy progressed, while others continued to display anger towards their children and other people in their lives. I will briefly substantiate this argument, and discuss the clinical implications of intervention.

Marlene stated that she felt less angry towards Leon, and her demeanour in therapy also changed as a result. Patricia told me that she understood her child better. She also said that she had more compassion towards Sue; and she started to buy her

child small gifts in appreciation of good behaviour. Linda's angry retorts about Tony's oppositional behaviour also subsided towards the latter half of therapy; and Hadil's angry descriptions of Ashraf's behaviour was noticeably toned down after she had acquired basic knowledge about schizophrenia.

Patricia stated that she gained insight into her child's behaviour after we had covered Sue's post-ictal psychosis and autism traits. I believe that this process led to the partial refutation of blaming attributions, which might have lowered Patricia's anger. Similar trends were observed with Hadil and Linda after psychoeducation and thought modification had facilitated the reattribution of intentionality and responsibility.

Sarah remained angry at Ethan. Her insistence on reciprocating aggression was another indication that her anger towards him did not lessen through the course of therapy.

Sarah's confrontational management of Ethan's behaviour was also an example of outwardly-directed anger. It was noticeable that Linda, Hadil and Marlene tended to direct anger outwards. Examples include Linda's confrontations with Tony and Kim; and Marlene's conflict with Leon. Hadil was also candid and criticised Ashraf in his presence.

At times, Linda, Marlene, Hadil and Patricia also directed their anger inwards. They often tried to suppress their angry feelings towards their children and other family members through deliberate efforts to become calmer and obtain control over their emotions. Although Marlene's relationship with Leon improved, it is interesting to note that she continued to express anger about his behaviour at home. She

confronted him less often, but she continued to display anger towards him during their arguments.

Parental anger implies heightened arousal, which could potentially sustain the child's aggressive behaviour through reciprocal reinforcement (McDonnell, 2010). Within the context of intellectual disability services and the child's aggressive behaviour, pertinent displays of parental anger could potentially have a negative impact on the management of the child's behavioural difficulties.

4.3.5 Conclusions and clinical implications

As I have described in Section 4.3, the participating mothers of this study presented with specific psychological problems that had an enduring impact on their ability to cope with adverse caregiving events.

Not only did mental health problems influence maternal reactions to their children's behavioural difficulties, distressing aspects of caregiving also perpetuated different psychological problems among some of the participants. For example, Ashraf's behaviour contributed to Hadil's depression. However, Hadil's depression also depleted her energy to actively deal with Ashraf's behaviour.

Family research in the ID field has often cited maternal depressive symptoms and parental stress as putative consequences of adverse caregiving experiences (Emerson et al., 2006). Against this, a small number of studies have also recognised parental personality traits as having a potential impact on parental coping among mothers and fathers of children who have ID (Glidden et al., 2006; Glidden et al., 2010; Glidden & Natcher, 2009; Jobe & Glidden, 2008).

4.4 The Unavailability or Inadequacy of Formal Support Services in the Public Sector

Besides financial stressors, all the participants reported negative experiences regarding the lack or inadequacy of available public services for their children who were diagnosed with ID.

With the exception of Patricia's daughter, none of the other children attended any form of sheltered employment, skills and development training or employment in the open labour market. In fact, although four of the other children were previously placed in sheltered employment, all of them were expelled because of their behavioural difficulties: Cindy's obsessionalities led to her expulsion; and Tony's psychosis and physical aggression made her placement in a workshop unsustainable. Together with paranoid delusions, Ashraf's refusal to attend the mosque also compromised his placement in a training institute; and from Marlene's reports, Karin's psychiatric problems led to her daughter's eventual refusal to attend a day centre and her eventual expulsion.

Adnams (2010) has described the inadequacy of governmental and non-governmental services for adults who have ID across South Africa. Participating mothers received feedback from different services that their children could not be accommodated in their organisation because of a lack of infrastructure and resources to deal with their children's behavioural difficulties. It was therefore up to the participating mothers to manage their children's behaviour during the day.

Literature in the ID field has also long recognised the negative ramifications of suboptimal activity scheduling and boredom on behavioural difficulties and the emotional well-being of persons who have ID (e.g., Hodapp, Burack, & Zigler, 1998;

McDonnell, 2010; Reed, 1997). Sarah told me that she spent most of her days with Ethan in an unstructured environment; and Cindy spent her days at home with her father.

Linda, Marlene, Hadil and Patricia also reported negative experiences with the district health system after their children had developed complicated medical or psychiatric conditions. Marlene recounted repeated incidents when she felt frustrated by the hours they had to wait to be assisted at the district hospital when Karin required acute psychiatric treatment.

Patricia described an earlier experience when Sue was treated in hospital for pneumonia. Notwithstanding her repeated warnings that Sue's oxygen mask could dislodge when she was having a nocturnal seizure, she was called the following morning with the news that they were resuscitating her daughter after her mask dislodged during the night.

Likewise, the narratives of Hadil's sessions contain various examples of nursing care that left this participant with feelings of distress, anger and resentment.

From the abovementioned examples and other incidents that were disclosed in therapy or during post-intervention interviews, it is evident that the majority of participants were dissatisfied and distressed about the health support their children received.

The service shortcomings of the respective public departments were not restricted to the lack of appropriate sheltered employment opportunities for their children and their offspring's indifferent medical care at district or tertiary levels.

At the time of therapy, we were only three full time clinical psychologists that worked in dedicated ID services in the Western Cape, a province with a population of approximately six million people (Statistics South Africa, 2013). In the context of a scarce resource setting, the participating mothers' children received psychological intervention but not necessarily individualised behavioural management programmes.

It is conceivable that inadequate behavioural support contributed to high levels of parental stress. A well-designed behavioural support programme would potentially reduce their children's aggression and other behavioural difficulties, thereby lowering parental stress.

4.4.1 The clinical implications of findings

The presence of prominent financial strain could have a negative impact on the coping resources of the primary caregivers of adults who have ID to manage their children's behavioural difficulties. In fact, one of the findings of this study is that material hardship was often associated with family conflict. This finding was consistent across all the case studies. It is therefore important to consider possible financial stresses and family functioning that could indirectly elevate parental stress among mothers of adults who have ID and marked displays of problem behaviours.

CHAPTER FIVE: CONCLUSION AND RECOMMENDATIONS

5.1 Concluding Remarks

The previous chapter described the main themes and clinical implications of the study. Many of the themes that I described resonate broadly with the findings from larger studies that have investigated the phenomena of parental stress among mothers of adults who have ID (Blacher & McIntyre, 2006; Gallagher & Whiteley, 2013; Ha et al., 2008; Hassall et al., 2005; Heller et al., 1997; C. Hill & Rose, 2009; Kim et al., 2003; Pruchno & Meeks, 2004; Totsika et al., 2011; Woodman & Hauser-Cram, 2013).

I shall draw the themes together by discussing the fundamental clinical implications of the study's findings.

All the participants presented with prominent cognitive distortions about caregiving. As described in the previous two chapters, most of these negative automatic beliefs were centred on perceptions of helplessness, hopelessness, a lack of adequate parental control and a generalised sense of inadequacy about their ability to manage distressing caregiving demands.

All the participants reported demanding and taxing caregiving experiences that exceeded their resources to cope with stress. It was also noticeable that reports of distressing caregiving encounters went beyond the child's aggressive behaviour: Patricia and Linda had to contend with the high medical support needs of their children's epilepsy; Hadil had to balance Ashraf's high behavioural support needs against her other compounded caregiving responsibilities; Cindy's wandering behaviour was as distressing to Jeanette as her daughter's aggressive outbursts; and Patricia repeatedly described Sue's repetitive behaviours as stressful. Sarah

was annoyed about Ethan's love for sugary snacks and his habit of throwing shoes, socks and other clothing on the roof. When her child relapsed into mania, Marlene was worried about Karin's insomnia, her ritualistic packing and unpacking as well as her daughter's disorganised and disoriented behaviour. This went far beyond concerns about her child's verbal and physical aggression.

At various intervals across the intervention, all six participants presented with different combinations of overgeneralised beliefs, catastrophising, all-or-nothing thinking, inferential thinking and selective abstractions about the breadth and depth of their caregiving stressors. The evidence from disputation suggests that, at times, the participants clustered and intertwined different spatial, temporal, categorical and aetiological caregiving constructs together on a cognitive level. As a result, many reports of distress, sadness, anger, helplessness and hopelessness were generalised to represent caregiving as a whole and not the specific components of caregiving that were at the time responsible for maternal distress.

We were often, but not always, able to identify pertinent activating events such as an episode of aggression, other behavioural difficulties, family conflict, inadequate family support, and distressing experiences when accessing formal support. There were also internal triggers that offset maternal distress, e.g., an internal sense of incompetence to manage episodes of the child's aggression, fearful appraisals, misattributions about the child's behaviour, and rumination about the significance of adverse caregiving events in the past. Yet parental beliefs were not always adequately aligned to the specific precipitants or setting events.

For example, Patricia continued to experience catastrophic beliefs when anticipating Sue's behavioural outbursts even when her daughter was at the workshop. She did

not adequately distinguish between periods of low risk and elevated risk, resulting in maintained apprehension, worry and distress. Hadil magnified the significance of her brother-in-law's warning that her children would have problems and continued to use emotional reasoning about the event four decades after it took place. She also continued to be distressed about Ashraf's behaviour in the here-and-now. Though she recognised that an underlying psychosis was partly responsible for Ashraf's behaviour, her experience was that the psychotic symptoms were to an extent under voluntary control, and caused in part by her – an overt rebelling against her parenting.

In this study, CBT attempted to address some of these cognitive distortions about distressing aspects of caregiving in a systematic manner. Many of the cognitive methods that were implemented shared a singular focus: to attempt to restructure maternal beliefs by collaboratively aligning it closer to the specific distressing aspects of specific caregiving encounters.

Following CBT intervention, Patricia grasped that Sue was not at home all the time and that constant vigilance was not required. She also realised that her fearful anticipation of catastrophic outcomes secondary to Sue's aggression was linked with earlier maternal experiences regarding her daughter's epilepsy. These changes were insufficient to significantly improve her negative mood and high levels of parental stress.

Linda processed some of her unfinished bereavement about the loss of a healthy child, thereby recognising the role of formative influences on her contemporary expressions of sadness and loss when she saw her child's cognitive decline. On a cognitive level, Linda was able to attribute Tony's behavioural problems more

accurately to the underlying psychiatric and medical maintaining factors rather than her daughter's intellectual disability.

Similarly, Hadil reported a sense of relief and a lessening of feelings of guilt and perceptions that she was at fault after she had recognised that Ashraf's behaviour was almost solely accounted for by his psychosis.

Marlene became increasingly aware that her conflict with Leon ignited old memories of an abusive marriage. Her son's constant accusations during their arguments about the fact that she stayed in an abusive marriage made her feel guilty. Once she started to acknowledge how disempowered she was at the time, her self-blame lessened and she was subsequently able to become more assertive towards Leon.

Jeanette used religion to positively reappraise the meaning of negative home circumstances. While her religious beliefs carried her through difficult times, we were able to systematically streamline some of her coping strategies against persistent stressors in a more systematic fashion. She continued to minimise many of her concerns about Cindy's caregiving at home, perhaps because she lacked the agency to change some of the maintaining conditions. But her agency was simultaneously enhanced when she changed her management of Cindy's obsessional behaviour related to the use of her mobile phone, the safe-keeping of medication, and the decision to confront her husband only when he was not under the influence of alcohol.

Sarah's negative automatic thoughts and misattributions about the antecedents, setting events and maintaining conditions of Ethan's behaviour were less amenable to CBT. Yet on a conceptual level her conflicting beliefs about the biological determinism and intentional behaviour behind Ethan's aggression were readily

observable. Distressing aspects of his behavioural problems were generalised to represent her entire caregiving experience:

Sarah: I cannot be happy if Ethan is around.

These negative automatic beliefs may have significant clinical implications when psychotherapists and other health care professionals provide behavioural support or other psychotherapeutic initiatives for family-based adults who have ID and severe behavioural difficulties with or without co-morbid medical and psychiatric symptoms:

- First, it was useful to distinguish aggression from the other behavioural problems in the child's profile. In busy clinical settings, parents may not automatically voice their concern about the other behavioural problems if aggression is severe and persistent. It is therefore useful to notice that, in this study, other behavioural problems were at times just as distressing.
- Second, because the participants tended to cluster different psychiatric, medical and intellectual disability diagnoses together when ascribing the causality of their children's behaviour, psychoeducation about the child's diagnoses may be a useful intervention strategy to assist in behavioural management programmes.
- Third, Wright and his colleagues (2006, p. 48) contend that the "chronicity and complexity" of presenting problems generally inform the duration of treatment. All six of the participants reported longstanding caregiving distress that often spanned over the course of decades. I described the role of earlier formative influences on contemporary caregiving perceptions and parental practices, especially in the case of the participants whose children had high medical

support needs. The role of other complex contextual social factors was described and different aspects of maternal mental health were identified.

Based on the complex presentation of chronic psychological problems, it would probably have been advantageous to continue psychotherapy with, particularly, Patricia, Hadil, Marlene and Sarah. Unfortunately, the time limitations and other practical constraints such as transport problems prevented us from having more sessions. However, in the context of scarce resources, it should also be acknowledged that these parents already received far more treatment relative to the vast majority of other South African parents.

It is conceivable that some of the referrals in clinical settings would represent complex family dynamics and prominent social factors that are, again, not necessarily overtly described when clinicians rightfully focus on systematic strategies to address the child's behavioural difficulties.

Yet as clinicians we have high expectations of the capacity of primary caregivers when we conduct functional assessments and implement differential reinforcement strategies. In the clinical setting where the research took place, children seldom attended psychotherapy without being accompanied by their caregivers. While the child's well-being remains the core business of dedicated services for children and adults who have ID, clinical signs of distress in the caregiver could well signify psychological problems on a personal level that have a significant bearing on the parent's capacity to provide optimal care. Besides the possible implications for the child, the well-being of mothers deserves clinical attention in its own right. Appropriate referrals to qualified mental health practitioners could therefore be

considered if maternal distress emerges from self-report or whilst implementing support programmes for their children.

- Fourth, the case studies highlighted many caregiving challenges that were linked with the participants' life-stage transition from midlife to old age. Examples included the management of chronic medical conditions, concerns about the future caregiving of the child should the mother be unable to continue caregiving; and reports of fatigue and exhaustion that participants like Hadil also linked with her chronological age.

These findings were in keeping with available literature that emphasises the role of developmental considerations when clinicians conceptualise parental stress, depressive symptoms and other caregiving challenges among parents of children who have ID (e.g., Heller et al., 2007; Seltzer et al., 2011).

- Last, while numerous cognitive distortions were identified, it was evident that many of the reported caregiving experiences and subsequent descriptions of maternal distress were embedded in stressful events that were less readily amenable to problem-solving. Examples included experiences of intimate partner violence, long histories of substance dependence among family members, the management of chronic medical health conditions, experiences of violent crime, and the unavailability of residential placement to persons who have ID and aggression.

Persistent stressors, such as the examples mentioned above, require the assistance of different professional stakeholders across different agencies and services.

When considering the prognosis of the six participants in terms of their parental stress and caregiving capacity, I believe that it is important to look at each case on an individual level. Multiple factors should be considered that include the following:

- The availability of appropriate social support from family members and their extended support circle.
- The family dynamics and interaction between the child who has disability and his or her siblings.
- The availability of adequate practical resources.
- The time available to provide caregiving against other daily responsibilities.
- The quality, availability and accessibility of formal health support.
- The possibility of group home placement in the future.
- Other mental health problems that may impact on the parent's capacity to provide continuous care.
- Maternal physical health and chronic medical conditions.
- The possibility of unexpected traumatic life events.
- The extent of maternal resilience and sense of coherence.
- The chronicity of the child's existing behavioural difficulties.
- The child's behavioural profile and behavioural support needs.
- The child's psychiatric and medical support needs.

Measured against these factors, it is recognised that the six participants will continue to face considerable caregiving and personal challenges across many of the social, personal and caregiving domains of their functioning. Thus, Jeanette's retirement could possibly provide her with more opportunities to keep the peace between Cindy and her husband, but socio-economic stressors would most likely remain. Linda will need to seek alternative caregiving arrangements because of her ageing parents'

anticipated move to a residential care facility. Tony's deteriorating health and cognitive decline could also maintain parental stress. Hadil's frail physical health is of concern together with Ashraf's persistent psychosis. Sarah's capacity to provide caregiving is of concern, and I am aware that social services got involved with Ethan's care shortly after therapy had been terminated. Marlene has considerable support and she has also progressed with addressing family conflict that impacted negatively on caregiving. Patricia's caregiving distress may respond positively to pharmacological treatment aimed at reducing generalised anxiety and depression. However, Sue's epilepsy profile and psychosis are persistent and the biological base of her behavioural difficulties makes her behaviour more difficult to manage.

5.2 The Use of a Case-Based Design: Methodological Strengths and Limitations and Suggestions for Future Research

The main strength of this study lies in the in-depth descriptions and analysis of psychotherapy process involving a small number of participants. Rich descriptions elicited prominent contextual variables that had a noticeable bearing on the ability of mothers to cope with their children's aggression and other demanding caregiving challenges. This study also represented, to my knowledge, a small first step in South African developmental disability family research involving a specific group of parents in a real life clinical setting: those whose children presented with severe aggression.

Through the process of my obtaining a personal history of relevant background information about the presenting problems and through the interviews that were conducted before the onset of psychotherapy, the participating mothers shared many of their caregiving experiences that led to elevated levels of parental stress and symptoms of maternal depression. In line with the strengths of case study research,

I am hopeful that the production of narrative texts and the interpretation of process from the perspective of the therapist will be of use to other clinicians who are interested in working with families of persons who have ID and behavioural difficulties.

Credibility was enhanced by producing rich descriptions of the therapy process, thereby allowing the reader to evaluate the trustworthiness of findings against his existing knowledge-base. As described in Chapter Two and Appendix A, the interrogation of themes that emerged from thematic analysis in peer supervision provided additional external credibility. As part of this process, the other psychotherapist independently analysed the first and last case studies. She also critically assessed the themes that emerged from the other cases. With transcripts, audio-sessions and the thematic analysis notes made available, external credibility was enhanced after she had found convergent themes in the first and last cases. She also found that the thematic analysis of the other case studies was consistent with the presented research material of each case. Credibility was also achieved by making the written transcripts available to another clinical psychologist and psychotherapist with experience in the field of intellectual disability.

Dependability was achieved when a third party assessor randomly selected a written transcript and audio-recording from each case. She then counted the number of additions and omissions to ensure that the transcript met acceptable standards, i.e., that the meaning of dialogue captured in the audio recording was not altered by erroneous transcriptions. Another third party assessor was given access to the corpus of data to gauge the general readability and flow of information.

I have also provided an extensive account of my paradigmatic and epistemological position in Appendix A. In this writing I covered the use of researcher subjectivity to interpret themes in clinical research, the dilemmas of researcher-clinicians in psychotherapy studies, and my understanding of caregiving experiences within the psychotherapy context. The clarification of my epistemological position contributes towards clarifying the application of qualitative methodology in this study against post-positivist and social constructionist discourses within qualitative inquiry (Ponterotto, Kuriakose, & Granovskaya, 2008).

The study has numerous limitations: First, despite proponents of contemporary case study psychotherapy research advocating the use of case-by-case replications to allow a degree of generalisability, the small number of participants and convenience sampling are detractors from such claims (e.g., McLeod, 2012).

Second, the fact that I conducted the post-psychotherapy interviews might have made it difficult for participants to openly express concerns and negative comments about their experiences of psychotherapy to their therapist. It would have undoubtedly increased the credibility of these interviews if another psychotherapist had facilitated the process. Transport difficulties and the work responsibilities of some of the participants did not permit a joint interview with a second researcher. The study lacked the funding to employ a skilled research assistant to help with the process of conducting interviews and psychometric assessments that were widely dispersed throughout the period taken to complete the case studies.

Third, the same argument pertains to the fact that I conducted the psychometric assessments: participants might have completed their assessments in a manner that magnified therapeutic gain, especially if they were reluctant to disappoint their

therapist with whom they had formed a relationship. In this context, however, McLeod (2011) cautions researchers about the possibility that participants may feel uncomfortable to hand in self-report rating scales to relative strangers.

I explained in detail the process of psychometric assessment to participants and the need to be as honest as possible when ratings were given. Five of the participants were able to complete the tests on their own once instructions were given, although I was present in the office if they had any queries about specific items. In order to avoid potential discomfort, I also avoided looking at the test results while they were completing assessments. It should also be noted that Patricia, Hadil and Sarah's follow-up PSI-II scores showed limited improvement from baseline.

Fourth, repeated baseline measurements would have provided more credible observations of the psychological well-being of parents before the onset of psychotherapy. The execution of this strategy was unfortunately not possible because of practical considerations, financial constraints and time limitations.

Last, the study did not include isiXhosa-speaking participants. I was unsuccessful in recruiting a Xhosa-speaking participant with adequate fluency in English. Although the small sample size precluded strong claims to generalisability, in the context of the study's qualitative embeddedness the representation by a member of the third language group in the Western Cape would have added valuable insight and depth.

The reality of research in low-resource contexts such as my place of work is that some of the logistical choices made present methodological challenges. Elsewhere, a colleague and I (Capri & Coetzee, 2012) have commented on the rights of people who have ID to participate in research. This is an issue which is even more urgent in the majority world, of which South Africa is a part. Practical challenges do constrain

methodological rigour, but my belief is that if limitations are acknowledged, it is important to begin a process of systematic recording of local experiences and challenges. This study, therefore, represents a small first step in South African family research of adults who have ID and aggression. There have been challenges in the work, but the data are the first to record reports of experiences of parents such as these in South Africa. It is clear that there is a need for future research that would include quantitative and qualitative studies.

Population-based studies could establish the prevalence of parental stress, depressive symptoms and other negative parental states such as anger and anxiety among South African parents. Epidemiological research could aggregate discrete measurements of parental distress and positive aspects of caregiving against different independent variables such as demographic information, available formal support to children, socio-economic position, the child's behavioural difficulties, and co-morbid psychiatric symptoms in the profiles of mothers and children.

The study explored different reported caregiving experiences from the perspective of the therapist in a clinical setting within the co-constructed space of psychotherapy. The use of participatory discourse analysis in focus groups could provide a platform for parents to participate in research projects that will generate more knowledge about their caregiving experiences on a phenomenological level. Such groups could include parents of children and adults who have developmental disability without prominent behavioural difficulties. It will also be important to explore the positive caregiving experiences among South African parents in this group.

Case studies are ill-equipped to inform service-planning and organisational design (McLeod, 2012). The participants of this study repeatedly described service-

shortcomings and inadequate formal support across health, vocational and residential services. Future research should focus on South African disability services in terms of organisational design, legislation and the service-packages that are on offer.

The findings of this study suggest that the support needs of distressed mothers of children who have ID and behavioural problems cannot be separated from the medical, social and behavioural support needs required by their children. Future studies could explore the use of formal psychological or behavioural support to attend to the child's behavioural problems in the South African context, e.g., the use of low arousal approaches (McDonnell, 2010) or differential reinforcement schedules (Chowdhury & Benson, 2011; Matson et al., 2012).

Larger intervention studies could investigate whether the rendering of formal behavioural support to assist in the management of problem behaviours has a discernible impact on parental stress among South African mothers of children and adults who have ID.

REFERENCES

- Abidin, R. R. (1995). *Parenting Stress Index – Third edition – Professional manual*. Lutz: Psychological Assessment Resources, Incorporated.
- Adato, M., Carter, R., & May, J. (2006). Exploring poverty traps and social exclusion in South Africa using qualitative and quantitative data. *Journal of Development Studies*, 42(2), 226-247.
- Adnams, C. M. (2010). Perspectives of intellectual disability in South Africa: epidemiology, policy, services for children and adults. *Current Opinion in Psychiatry*, 23(5), 436-440.
- Agesa, R. U., Agesa, J., & Bongani, G. (2010). Higher residual wage dispersion for white workers in post apartheid South Africa, 1995-2006: Composition effects or higher skill prices? *The Journal of Developing Areas*, 44(1), 71-100.
- Ajuwon, P. M., & Brown, I. (2012). Family quality of life in Nigeria. *Journal of Intellectual Disability Research*, 56(1), 61-70.
- Allen, D. (2000). Recent research on physical aggression in persons with intellectual disability: An overview. *Journal of Intellectual & Developmental Disability*, 25(1), 41-57
- Allen, D., & Davies, D. (2007). Challenging behaviour and psychiatric disorder in intellectual Disability. *Current Opinion in Psychiatry* 20(1), 450-455.
- Allen, D., Lowe, K., Matthews, H., & Anness, V. (2012). Screening for psychiatric disorders in a total population of adults with intellectual disability and challenging behaviour using the PAS-ADD Checklist. *Journal of Applied Research in Intellectual Disabilities*, 25(4), 342-349.
- Alexander, R. T., Green, F. N., O'Mahony, B., Gunaratna, I. J., Gangadharan, S. K., & Hoare S. (2010). Personality disorders in offenders with intellectual

- disability: A comparison of clinical, forensic and outcome variables and implications for service provision. *Journal of Intellectual Disability Research* 54(7), 1-9.
- American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Anclair, M., & Hiltunen, A. J. (2014). Cognitive behavioral therapy for stress-related problems: Two single-case studies of parents of children with disabilities. *Clinical Case Studies*, 13(6), 472-486.
- Andronicos, D. (2007). *Coping with burnout: Overcoming common problems*. London: Sheldon Press.
- Antonovsky, A. (1979). *Health, stress and coping*. San Francisco: Jossey-Bass Publishers.
- Armstrong, H., & Dagnan, D. (2011). Mothers of children who have an intellectual disability: Their attributions, emotions and behavioural responses to their child's challenging behaviour. *Journal of Applied Research in Intellectual Disabilities*, 24(5), 459-467.
- Arslan, C. (2010). An investigation of anger and anger expression in terms of coping with stress and interpersonal problem-solving. *Educational Sciences: Theory & Practice*, 10(1), 25-43.
- Awad, A. G., & Voruganti, L. N. P. (2008). The burden of schizophrenia on caregivers: A review. *Pharmacoeconomics*, 26(2), 149-162.
- Bailey, D. B., Golden, R., Roberts, J., & Ford, A. (2007). Maternal depression and developmental disability: Research critique. *Mental Retardation and Developmental Disabilities Reviews*, 13(4), 321-329.
- Baldwin, E. N. (2014). Recognizing guilt and shame: Therapeutic

- ruptures with parents of children in psychotherapy. *Psychoanalytic Social Work*, 21(1-2), 2-18.
- Barker, E. T., Greenberg, J. S., Seltzer, M. M., & Almeida, D. M. (2012). Brief report: Daily stress and cortisol patterns in parents of adult children with a serious mental illness. *Health Psychology*, 31(1), 130-134.
- Barlow, D. H., Nock, M. K., & Hersen, M. (2009). *Single case experimental designs: Strategies for studying behavior change*. Boston: Pearson.
- Bateman, A., Brown, D., & Pedder, J. (2010). *Introduction to psychotherapy: An outline of psychodynamic principles and practice* (4th ed.). London: Routledge.
- Bauman, E. M., Haaga, D. A. F., & Dutton, M. A. (2008). Coping with intimate partner violence: Battered women's use and perceived helpfulness of emotion-focused coping strategies. *Journal of Aggression, Maltreatment & Trauma*, 17(1), 23-41.
- Beck, A. T., & Alford, B. A. (2009). *Depression: Causes and treatment* (2nd ed.). Philadelphia, PA: University of Pennsylvania Press.
- Beck, A. T., Steer, R. A., Ball, R., & Ranieri, W. F. (1996). Comparison of Beck Depression Inventories-IA and -II in psychiatric outpatients. *Journal of Personality Assessment*, 67(3), 588-597.
- Beck, A. T., Steer, R. A., & Brown, G. (1996). *Manual for the Beck Depression Inventory-II*. San Antonio, TX: Psychological Corporation.
- Beck, J. S. (1995). *Cognitive therapy: Basics and beyond*. New York, NY: The Guilford Press.
- Belchic, J. K. (1996). Stress, social support, and sense of parenting competence: A comparison of mothers and fathers of children with autism, Down syndrome,

- and normal development across the family life cycle. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 57(2-A), 574.
- Benson, B. A., & Brooks, W. T. (2008). Aggressive challenging behaviour and intellectual disability. *Current Opinion in Psychiatry*, 21(1), 454-458.
- Benson, P. R., & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism & Developmental Disorders*, 39(2), 350-362.
- Bentall, R. P., & Kaney, S. (2005). Attributional lability in depression and paranoia. *British Journal of Clinical Psychology*, 44(4), 475-488.
- Benzies, K. M., Trute, B., & Worthington, C. (2013). Maternal self-efficacy and family adjustment in households with children with serious disability. *Journal of Family Studies*, 19(1), 35-43.
- Ben-Zur, H., Duvdevany, I., & Lury, L. (2005). Associations of social support and hardiness with mental health among mothers of adult children with intellectual disability. *Journal of Intellectual Disability Research*, 49(1), 54-62.
- Berg-Nielsen, T. S., Vikan, A., & Dahl, A. A. (2002). Parenting related to child and parental psychopathology: A descriptive review of the literature. *Clinical Child Psychology and Psychiatry*, 7(4), 529-552.
- Bhaumik, S., Gangadharan, S., Hiremath, A., & Russell, P. S. S. (2011). Psychological treatments in intellectual disability: The challenges of building a good evidence base. *The British Journal of Psychiatry*, 198(6), 428-430.
- Bhaumik, S., Tyrer, F. C., McGrother, S. K., & Ganghadaran S. K. (2008). Psychiatric service use and psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research*, 52(11), 986-995.

- Blacher, J., Begum, G. F., Marcoulides, G. A., & Baker, B. L. (2013). Longitudinal perspectives of child positive impact on families: Relationship to disability and culture. *American Journal of Intellectual and Developmental Disabilities*, 118(2), 141-155.
- Blacher, J., & Hatton, C. (2001). Current perspectives on family research in mental retardation. *Current Opinion in Psychiatry*, 14(5), 477-482.
- Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorder in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research*, 50(3), 184-198.
- Blacher, J., Neece, C. L., & Paczkowski, E. (2005). Families and intellectual disability. *Current Opinion in Psychiatry*, 18(5), 507-513.
- Bourgeois, J. A., Coffey, S. M., Rivera, S. M., Hessel, D., Gane, L. W., Tassone, F., . . . Hagerman, A. J. (2009). A review of Fragile X premutation disorders: Expanding the psychiatric perspective. *The Journal of Clinical Psychiatry*, 70(6), 852-862.
- Bowers, J. W. (2002). A preliminary investigation of the additive effect of a parent training protocol in the treatment of phobic children. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 63(2-B), 1015.
- Brannan, A. M., & Heflinger, C. A. (2001). Distinguishing caregiver strain from psychological distress: Modeling the relationships among child, family, and caregiver variables. *Journal of Child and Family Studies*, 10(4), 405-418.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Brewin, C. R. (1985). Depression and causal attributions: What is their relation? *Psychological Bulletin*, 98(2), 297-309.

- Brinkmann, S., Jacobsen, M. H., & Kristiansen, S. (2014). Historical overview of qualitative research in the social sciences. In P. Leavy (Ed.), *The Oxford Handbook of Qualitative Research* (pp. 17-42). Oxford: Oxford University Press.
- Brooks, A., & Clarke, L. (2011). Combining client-centred therapy with attribution theory. *Mental Health Practice*, 14(9), 34-37.
- Bulik, C. M., Berkman, N. D., Brownley, K. A., Sedway, J. A., & Lohr, K. N. (2007). Anorexia Nervosa treatment: A systematic review of randomised controlled trials. *International Journal of Eating Disorders*, 40(4), 310-320.
- Calvete, E., Corral, C. S., & Estévez, A. (2007). Cognitive and coping mechanisms in the interplay between intimate partner violence and depression. *Anxiety, Stress, & Coping*, 20(4), 369-382.
- Cameron, L., & Murphy, J. (2006). Obtaining consent to participate in research: The issues involved in including people with a range of learning and communication disabilities. *British Journal of Learning Disabilities*, 34(2), 113-120.
- Campis, L. K., Lyman, R. D., & Prentice-Dunn, S. (1986). The Parental Locus of Control Scale: Development and validation. *Journal of Clinical Child Psychology*, 15(3), 260-267.
- Capri, C., & Buckle, C. (2014). 'We have to be satisfied with the scraps': South African nurses' experiences of care on adult psychiatric intellectual disability inpatient wards. *Journal of Applied Research in Intellectual Disabilities*. doi:10.1111/jar.12118

- Capri, C., & Coetzee, O. (2012). On the unethicity of disablism: Excluding intellectually impaired individuals from participating in research can be unethical. *African Journal of Disability*. doi.org/10.4102/ajod.v1i1.23
- Carlson, G., Armitstead, C., Rodger, S., & Liddle, G. (2010). Parents' experiences of the provision of community-based family support and therapy services utilizing the Strengths approach and natural learning environments. *Journal of Applied Research in Intellectual Disabilities*, 23(6), 560-572.
- Chadwick, D. D., Mannan, H., Iriarte, E. G., McConkey, R., O'Brien, P., Finlay, F., . . . Harrington, G. (2013). Family voices: Life for family carers of people with intellectual disabilities in Ireland. *Journal of Applied Research in Intellectual Disabilities*, 26(2), 119-132.
- Chamberlain, K., Camic, P., Yardley, L. (2004). Qualitative analysis of experience: Grounded theory and case studies. In D. F. Marks & L. Yardley (Eds.), *Research methods for clinical and health psychology* (pp. 69-89). London: Sage Publications Limited.
- Chou, Y. C., Pu, C-Y., Fu, L-Y., & Kröger, T. (2010). Depressive symptoms in older female carers of adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 54(12), 1031-1044.
- Chowdhury, M., & Benson, B. A. (2011). Use of differential reinforcement to reduce behavior problems in adults with intellectual disabilities: A methodological review. *Research in Developmental Disabilities*, 32(2), 383-394.
- Christianson, A. L., Zwane, M. E., Manga, P., Rosen, E., Venter, A., Downs, D., & Kromberg, J. G. R. (2002). Children with intellectual disability in rural South Africa: Prevalence and associated disability. *Journal of Intellectual Disability Research*, 46(2), 179-186.

- Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Over-coming challenges and developing strategies for effective learning. *The Psychologist*, 26 (2), 120-123.
- Coetzee, O., & Johns, R. (2016). Development and the child with intellectual disability. In R. Johns & C. Adnams (Eds.), *Understanding Intellectual Disability: A Handbook for Families, Staff, Students and Professionals* (pp. 21-29). Cape Town: Western Cape Forum for Intellectual Disability.
- Cooper, S.-A., Smiley, E., Jackson, A., Finlayson, J., Allen, L., Mantry, D., & Morrison, J. (2009). Adults with intellectual disabilities: Prevalence, incidence and remission of aggressive behaviour and related factors. *Journal of Intellectual Disability Research*, 53(3), 217-232.
- Costa, P. T., Jr., & McCrae, R. R. (1992). *NEO PI-R professional manual*. Odessa, FL: Psychological Assessment Resources, Inc.
- Covic, T., Cumming, S. R., Pallant, J. F., Manolios, N., Emery, P., Conaghan, P. G., & Tennant, A. (2012). Depression and anxiety in patients with rheumatoid arthritis: Prevalence rates based on a comparison of the Depression, Anxiety and Stress Scale (DASS) and the Hospital, Anxiety and Depression Scale (HADS). *BMC Psychiatry*, 12(6), 2-10.
- Crocker, A. G., Mercier, C., Lachapelle, Y., Brunet, A., Morin, D., & Roy, M.-E. (2006). Prevalence and types of aggressive behaviour among adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 50(9), 652-666.
- Crocker, A. G., Prokić, A., Morin, D., & Reyes, A. (2014). Intellectual disability and co-occurring mental health and physical disorders in aggressive behaviour. *Journal of Intellectual Disability Research*, 58(11), 1032-1044.

- Cummins, R. A. (2001). The subjective well-being of people caring for a family member with a severe disability at home: A review. *Journal of Intellectual and Developmental Disability, 26*(1), 82-100.
- Cuskelly, M. (2006). Parents of adults with an intellectual disability. *Family Matters, 74*, 20-25.
- Dattilio, F. (2006). Does the case study have a future in the psychiatric literature? *International Journal of Psychiatry in Clinical Practice, 10*(3), 195-203.
- Dattilio, F. M., Edwards, D. J. A., & Fishman, D. B. (2010). Case studies within a mixed methods paradigm: Toward a resolution of the alienation between researcher and practitioner in psychotherapy research. *Psychotherapy Theory, Research, Practice, Training, 47*(4), 427-441.
- Deb, S., Thomas, M., & Bright, C. (2001). Mental disorder in adults with intellectual disability.1: Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research, 45*(6), 495-505.
- Deb, S., & Unwin G. L. (2007). Psychotropic medication for behaviour problems in people with intellectual disability: A review of the current literature. *Current Opinion in Psychiatry, 20*(5), 461-466.
- DeBaryshe, B. D., & Fryxell, D. (1998). A developmental perspective on anger: Family and peer contexts. *Psychology in the Schools, 35*(3), 205-216.
- Deffenbacher, J. L., Oetting, E. R., Thwaites, G. A., Lynch, R. S., Baker, D. A., Stark, R. S., . . . Eiswerth-Cox, L. (1996). State-trait anger theory and the utility of the Trait Anger Scale. *Journal of Counseling Psychology, 43*(2), 131-148.
- Dempsey, I., Keen, D., Pennell, D., O'Reilly, J., & Neilands, J. (2009). Parent stress, parenting competence and family-centered support to young children with an

- intellectual or developmental disability. *Research in Developmental Disabilities*, 30(3), 558-566.
- De Winter, C. F., Jansen, A. A. C., & Evenhuis, H. M. (2011). Physical conditions and challenging behaviour in people with intellectual disability: A systematic review. *Journal of Intellectual Disability Research*, 55(7), 675-698.
- Dillenburger, K., & McKerr, L. (2010). 'How long are we able to go on?' Issues faced by older family caregivers of adults with disabilities. *British Journal of Learning Disabilities*, 39(1), 29-38.
- Dilworth, J. A., Phillips, N., & Rose, J. (2011). Factors relating to staff attributions of control over challenging behaviour. *Journal of Applied Research in Intellectual Disabilities*, 24(1), 29-38.
- Dozois, D. J. A., Dobson, K. S., & Ahnberg, J. L. (1998). A psychometric evaluation of the Beck Depression Inventory-II. *Psychological Assessment*, 10(2), 83-89.
- Dreman, S. (2003). Family cohesiveness, flexibility and maternal anger: Boon or detriment to children's adjustment. *Journal of Divorce & Remarriage*, 39(1/2), 65-87.
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37(1), 39-52.
- Edwards, D. J. A. (2007). Collaborative versus adversarial stances in scientific discourse: Implications for the role of systematic case studies in the development of evidence-based practice in psychotherapy. *Pragmatic Case Studies in Psychotherapy*, 3(1), 6-34.

- Edwards, D. J. A. (2010a). Languages of science and the problem of applied clinical knowledge: A mixed methods appraisal of Eells' case formulation research. *Pragmatic Case Studies in Psychotherapy*, 6(4), 276-285.
- Edwards, D. J. A. (2010b). Using systematic case studies to investigate therapist responsiveness: Example from a case series of PTSD treatments. *Pragmatic Case Studies in Psychotherapy*, 6(4), 255-275.
- Edwards, D. J. A., Dattilio, F. M., & Bromley, D. B. (2004). Developing evidence-based practice: The role of case-based research. *Professional Psychology: Research and Practice*, 35(6), 589-597.
- Eells, T. D. (2007). Generating and generalizing knowledge about psychotherapy from pragmatic case studies. *Pragmatic Case Studies in Psychotherapy*, 3(1), 35-54.
- Einfeld, S. L., Stancliffe, R. J., Gray, K. M., Sofronoff, K., Rice, L., Emerson, E., & Yasamy, M. T. (2012). Interventions provided by parents for children with intellectual disabilities in low and middle income countries. *Journal of Applied Research in Intellectual Disabilities*, 25(2), 135-142.
- Eisenhower, A. & Blacher, J. (2006). Mothers of young adults with intellectual disability: Multiple roles, ethnicity and well-being. *Journal of Intellectual Disability Research*, 50(12), 905-916.
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38(3), 215-229.
- Emerson, E., & Hatton, C. (2009). Socioeconomic position, poverty and family research. *International Review of Research in Mental Retardation*, 37, 97-129.

- Emerson, E., Hatton, C., Llewellyn, G., Blacker, J., & Graham, H. (2006). Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities. *Journal of Intellectual Disability Research*, 50(12), 862-873.
- Emerson, E. & Llewellyn, G. (2008). The mental health of Australian mothers and fathers of young children at risk of disability. *Young People's Health*, 32(1), 53-59.
- Emerson, E., McCulloch, A., Graham, H., Blacher, J., Llewellyn, G., & Hatton, C. (2010). Socio-economic circumstances and risk of common psychiatric disorders among parents of young children with and without early cognitive delay in the UK. *American Journal on Intellectual and Developmental Disability*, 115, 30-42.
- Emerson, E., Yasamy, M. T., & Saxena, S. (2012). Scaling up support for children with developmental disabilities in low- and middle-income countries. *Journal of Applied Research in Intellectual Disabilities*, 25(2), 96-98.
- Esbensen, A. J., Seltzer, M. M., & Greenberg, J. S. (2006). Depressive symptoms in adults with mild and moderate intellectual disability and their relation to maternal well-being. *Journal of Policy and Practice in Intellectual Disabilities*, 3(4), 229-237.
- Farmer, E. M. Z., Burns, B. J., Angold, A., & Costello, E. J. (1997). Impact of children's mental health problems on families: relationships with service use. *Journal of Emotional and Behavioural Disorders*, 5(4), 230-238.
- Faust, H., & Scior, K. (2008). Mental health problems in young people with intellectual disabilities: The impact on parents. *Journal of Applied Research in Intellectual Disabilities*, 21(5), 414-424.

- Felce, D., Cohen, D., Willner, P., Rose, J., Kroese, B., Rose, N., . . . Hood, K. (2015). Cognitive behavioural anger management intervention for people with intellectual disabilities: costs of intervention and impact on health and social care resource use. *Journal of Intellectual Disability Research*, 59(1), 68-81.
- Felce, D., Kerr, M., & Hastings, R. P. (2009). A general practice-based study of the relationship between indicators of mental illness and challenging behaviour among adults with intellectual disabilities. *Journal of Intellectual Disability Research* 53(3), 243-254.
- Fishman, D. B. (2005). Editor's introduction to PCSP - From single case to database: A new method for enhancing qualitative psychotherapy research. *Pragmatic Case Studies in Psychotherapy*, 1(1), 1-50.
- Fishman, D. B. (2013). The Pragmatic case study method for creating rigorous and systematic, practitioner-friendly research. *Pragmatic Case Studies in Psychotherapy*, 9(4), 403-425.
- Flyvberg, B. (2005). Five misunderstandings about case-study research. In C. Seale, G. Gobo, J. F. Gubrium, & D. Silverman (Eds.), *Qualitative Research Practice* (pp. 420-434). London: SAGE Publications.
- Folkman, S. (1984). Personal control and stress and coping processes: A theoretical analysis. *Journal of Personality and Social Psychology*, 46(4), 839-852.
- Folkman, S., & Lazarus, R. S. (1988). *Ways of Coping Questionnaire: Manual, test booklet, scoring key*. Palo Alto, CA: Consulting Psychologists Press.
- Forgays, D. G., Forgays, D. K., & Spielberger, C. D. (1997). Factor structure of the State-Trait Anger Expression Inventory. *Journal of Personality Assessment*, 69(3), 497-507.

- Frey, K. S., Greenberg, M. T., & Fewell, R. R. (1989). Stress and coping among parents of handicapped children: a multidimensional approach. *American Journal of Mental Retardation*, 94(3), 240-249.
- Frie, R. (2003). Introduction: Between modernism and postmodernism: Rethinking psychological agency. In R. Frie (Ed.), *Understanding experience: Psychotherapy and postmodernism* (pp. 1-26). London: Routledge.
- Gallagher, S., & Whiteley, J. (2013). The association between stress and physical health in parents caring for children with intellectual disabilities is moderated by children's challenging behaviours. *Journal of Health Psychology*, 18(9), 1220-1231.
- Gelo, O. C. G., & Salvatore, S. (2016). A Dynamic systems approach to psychotherapy: A Meta-Theoretical framework for explaining psychotherapy change processes. *Journal of Counseling Psychology*.
doi:org/10.1037/cou0000150
- Gibaud-Wallaston, J., & Wandersman, L. P. (1978, August). *Development and utility of the Parenting Sense of Competence Scale*. Paper presented at the meeting of the American Psychological Association, Toronto, Canada.
- Gilmore, L. A., & Cuskelly, M. (2008). Factor structure of the parenting sense of competence scale using a normative sample. *Child Care, Health & Development*, 38(1), 48-55.
- Glidden, L. M., Bamberger, K. T., Turek, K. C., & Hill, K. L. (2010). Predicting mother/father-child Interactions: Parental personality and well-being, socioeconomic variables and child disability status. *Journal of Applied Research in Intellectual Disabilities*, 23(1), 3-13.

- Glidden, L. M., Billings, F. J., & Jobe, B. M. (2006). Personality, coping style and well-being of parents rearing children with developmental disabilities. *Journal of Intellectual Disability Research*, 50(12), 949-962.
- Glidden, L. M., & Natcher, A. L. (2009). Coping strategy use, personality, and adjustment of parents rearing children with developmental disabilities. *Journal of Intellectual Disability Research*, 53(12), 998-1013.
- Goodwin, R. D., Lavoie, K. L., Lemeshow, A. R., Jenkins, E., Brown, E. S., & Fedoronko, D. A. (2012). Depression, anxiety, and COPD: The unexamined role of nicotine dependence. *Nicotine & Tobacco Research*, 14(2), 176-183.
- Gohel, M., Mukherjee, S., & Choudhary, S. K. (2011). Psychosocial impact on the parents of mentally retarded children in Anand District. *Headline*, 2(2), 62-66.
- Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, 8(4), 597-607.
- Gordon, K. C., Friedman, M. A., Miller, I. W., & Gaertner, L. (2005). Marital attributions as moderators of the marital discord-depression link. *Journal of Social and Clinical Psychology*, 24(6), 876-893.
- Gould, R. L., Coulson, M. C., & Howard, R. J. (2012). Efficacy of cognitive behavioural therapy for anxiety disorders in older people: A meta-analysis and meta-regression of randomized controlled trials. *Journal of the American Geriatrics Society*, 60(2), 218-229.
- Grant, G., Ramcharan, P., & Flynn, M. (2007). Resilience in families with children and adult members with intellectual disabilities: Tracing elements of a psychosocial model. *Journal of Applied Research in Intellectual Disabilities*, 20(6), 563-575.

- Griffith, G. M., & Hastings, R. P. (2013). 'He's hard work, but he's worth it'. The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: A meta-synthesis of qualitative research. *Journal of Applied Research in Intellectual Disabilities*. doi:10.1111/jar.12073
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage.
- Gupta, R. K., & Kaur, H. (2010). Stress among parents with intellectual disability. *Asia Pacific Disability Rehabilitation Journal*, 21(2), 118-126.
- Ha, J-H., Hong, J., Seltzer, M. M., & Greenberg, J. S. (2008). Age and gender differences in the well-being of midlife and aging parents with children with mental health or developmental problems: Report of a national study. *Journal of Health and Social Behavior*, 49(3), 301-316.
- Hall, H. R., Neely-Barnes, S. L., Graff, J. C., Krcek, T. E., & Roberts, R. J. (2012). Parental stress in families of children with a genetic disorder/disability and the resiliency model of family stress, adjustment and adaptation. *Issues in Comprehensive Pediatric Nursing*, 35(1), 24-44.
- Hanson, W. E., Creswell, J. W., Clark, V. L. P., Petska, K. S., & Creswell, J. D. (2005). Mixed methods research designs in counseling psychology. *Journal of Counseling Psychology*, 52(2), 224-235.
- Hartley, S. L., Seltzer, M. M., Hong, J., Greenberg, J. S., Smith, L., Almeida, D., . . . Abbeduto, L. (2012). Cortisol response to behavior problems in FMR1 premutation mothers of adolescents and adults with fragile X syndrome: A diathesis-stress model. *International Journal of Behavioral Development*, 36(1), 53-61.

- Harvey, S. T., Boer, D., Meyer, L. H., & Evans, I. M. (2009). Updating a meta-analysis of intervention research with challenging behaviour: Treatment validity and standards of practice. *Journal of Intellectual & Developmental Disability, 34*(1), 67-80.
- Haskett, M. E., Ahern, L. S., Ward, C. S., & Allaire, J. C. (2006). Factor structure and validity of the Parenting Stress Index–Short Form. *Journal of Clinical Child and Adolescent Psychology, 35*(2), 302-312.
- Hassall, R., & Rose, J. (2005). Parental cognitions and adaptation to the demands of caring for a child with an intellectual disability: A review of the literature and implications for clinical interventions. *Behavioural and Cognitive Psychotherapy, 33*(1), 71-88.
- Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405-418.
- Hastings, R. P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual & Developmental Disability, 27*(3), 149-160.
- Hastings, R. P., & Beck, A. (2004). Practitioner Review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology & Psychiatry, 45*(8), 1338-1349.
- Hastings, R. P., & Brown, T. (2002). Behavioral problems of children with autism, parental self-efficacy, and mental health. *American Journal of Mental Retardation, 107*(3), 222-232.

- Hastings, R. P., Robertson, J., & Yasamy, M. T. (2012). Interventions for children with pervasive developmental disorders in low and middle income countries. *Journal of Applied Research in Intellectual Disabilities*, 25(2), 119-134.
- Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal of Mental Retardation*, 107(2), 116-127.
- Hatton, C., & Emerson, E. (2009). Does socioeconomic position moderate the impact of child behaviour problems on maternal health in South Asian families with a child with intellectual disabilities? *Journal of Intellectual and Developmental Disabilities*, 34(1), 10-16.
- Hatton, C., Emerson, E., Kirby, S., Kotwal, H., Baines, S., Hutchinson, C., . . . Marks, B. (2010). Majority and minority ethnic family carers of adults with intellectual disabilities: Perceptions of challenging behavior and family impact. *Journal of Applied Research in Intellectual Disabilities*, 23(1), 63-74.
- Hatton, C., Knussen, C., Sloper, P., & Turner, S. (1995). The stability of the Ways of Coping (Revised) Questionnaire over time in parents of children with Down's Syndrome: A research note. *Psychological Medicine: A Journal of Research in Psychiatry and the Allied Sciences*, 25(2), 419-422.
- Haugstvedt, K. T. S., Graff-Iversen, S., Bukholm, I. R. K., Haugli, L., & Hallberg, U. (2013). Processes of enhanced self-understanding during a counselling programme for parents of children with disabilities. *Scandinavian Journal of Caring Sciences*, 27(1), 108-116.
- Haveman, M., Van Berkum, G., Reijnders, R., & Heller, T. (1997). Differences in service needs, time demands, and caregiving burden among parents of

- persons with mental retardation across the life cycle. *Family Relations*, 46(4), 417-425.
- Hawley, C. A., Ward, A. B., Magney, A. R., & Long, J. (2003). Parental stress and burden following traumatic brain injury amongst children and adolescents. *Brain Injury*, 7(1), 1-23.
- Hayes, N. (2000). *Doing psychological research: Gathering and analysing data*. Maidenhead: Open University Press.
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(3), 629-642.
- Heller, T., Caldwell, J., & Factor, A. (2007). Aging family caregivers: Policies and practices. *Mental Retardation and Developmental Disabilities*, 13(2), 136-142.
- Heller, T., Hsieh, K., & Rowitz, L. (1997). Maternal and paternal caregiving of persons with mental retardation across the life span. *Family Relations*, 46(4), 407-415.
- Heyvaert, M., Maes, B., & Onghena, P. (2010). A meta-analysis of intervention effects on challenging behaviour among persons with intellectual disabilities. *Journal of Intellectual Disability Research*, 54(7), 634-649.
- Higgs, N. T. (2007). Measuring and understanding the well-being of South Africans: Everyday quality of life in South Africa. *Social Indicators Research*, 81(2), 331-356.
- Hill, C., & Rose, J. (2009). Parenting stress in mothers of adults with an intellectual disability: Parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research*, 53(12), 969-980.

- Hill, C. E., Chui, H., & Baumann, E. (2013). Revisiting and re-envisioning the outcome problem in psychotherapy: An argument to include individualized and qualitative measurement. *Psychotherapy, 50*(1), 68-76.
- Hodapp, R. M., Burack, J. A., & Zigler, E. (1998). Developmental approaches to mental retardation: A short introduction. In J. A. Burack, R. M. Hodapp, & E. Zigler (Eds.), *Handbook of mental retardation and development* (pp. 3-19). Cambridge: Cambridge University Press.
- Hoffman, S. G., Asnaani, A., Vonk, I. J. J., Sawyer, A. T., & Fang, A. (2012). The efficacy of cognitive behavioral therapy: A review of meta-analyses. *Cognitive Therapy and Research, 36*(5), 427-440.
- Holden, B., & Gitlesen, J. P. (2004). The association between severity of intellectual disability and psychiatric symptomatology. *Journal of Intellectual Disability Research, 48*(6), 556-562.
- Holden, B., & Gitlesen, J. P. (2009). The overlap between psychiatric symptoms and challenging behaviour: A preliminary study. *Research in Developmental Disability, 30*(2), 210-218.
- Hollway, W. (2015). *Knowing mothers: Researching maternal identity change*. New York, NY: Palgrave McMillan.
- Hollway, W. (2016). Emotional experience plus reflection: Countertransference and reflexivity in research. *The Psychotherapist, 62*, 19-21.
- Hollway, W., & Jefferson, T. (2013). *Doing qualitative research differently: A psychosocial approach* (2nd ed.). London: Sage Publishers Limited.
- Hudson, A. M., Matthews, J. M., Gavidia-Payne, S. T., Cameron, C. A., Mildon, R. L., Radler, G. A., & Nankervis, K. L. (2003). Evaluation of an intervention system

- for parents of children with intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research*, 47(4/5), 238-249.
- Hurley, A. D. (2008). Depression in adults with intellectual disability: Symptoms and challenging behaviour. *Journal of Intellectual Disability Research*, 52(11), 905-916.
- Iverson, K. M., Litwack, S. D., Pineles, S. L., Suvak, M. K., Vaughn, R. A., & Resick, P. A. (2013). Predictors of intimate partner violence revictimization: The relative impact of distinct PTSD symptoms, dissociation, and coping strategies. *Journal of Traumatic Stress*, 26(1), 102-110.
- Iwasaki, Y. (2001). Testing an optimal matching hypothesis of stress, coping and health: leisure and general coping. *Society and Leisure*, 24(1), 163-203.
- Jahoda, A., Dagnan, D., Stenfert Kroese, B., Pert, C., & Trower, P. (2009). Cognitive behavioural therapy: From face to face to a broader contextual understanding of change. *Journal of Intellectual Disability Research*, 53(9), 759-771.
- Jobe, B. M., & Glidden, L. M. (2008). Predicting maternal rewards and worries for the transition to adulthood of children with developmental disabilities. *Journal on Developmental Disabilities*, 14(1), 73-84.
- Joffe, H., & Yardley, L. (2004). Content and thematic analysis. In D. F. Yardley & L. Marks (Eds.), *Research methods for clinical and health psychology* (pp. 56-68). London: SAGE Publications.
- John, A. (2012). Stress among mothers of children with intellectual disabilities in urban India: Role of gender and maternal coping. *Journal of Applied Research in Intellectual Disabilities*, 25(4), 372-382.
- Johnston, C., & Mash, E. J. (1989). A measure of parenting satisfaction and efficacy. *Journal of Clinical Child Psychology*, 18(2), 167-175.

- Jokinen, N. S., & Brown, R. I. (2005). Family quality of life from the perspective of older parents. *Journal of Intellectual Disability Research*, 49(10), 789-793.
- Jones, T. L., & Prinz, R. J. (2005). Potential roles of parental self-efficacy in parent and child adjustment: A review. *Clinical Psychology Review*, 25(3), 341-363.
- Joyce, T., Ditchfield, H., & Harris, P. (2001). Challenging behaviour in community services. *Journal of Intellectual Disability Research*, 45(2), 130-138.
- Kanagaratnam, P., Mason, R., Hyman, I., Manuel, L., Berman, H., & Toner, B. (2012). Burden of womanhood: Tamil women's perceptions of coping with intimate partner violence. *Journal of Family Violence*, 27(7), 647-658.
- Karlsen, B., Oftedal, B., & Bru, E. (2011). The relationship between clinical indicators, coping styles, perceived support and diabetes-related distress among adults with type 2 diabetes. *Journal of Advanced Nursing*, 67(2), 391-401.
- Kazdin, A. E. (2007). Evidence-based treatment and practice: New opportunities to bridge clinical research and practice, enhance the knowledge base, and improve patient care. *American Psychologist*, 63(3), 146-159.
- Kearney, J. (2008). Mothers' resolution of their children's psychiatric diagnoses. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 69(5-B), 3296.
- Kelso, T., French, D., & Fernandez, M. (2005). Stress and coping in primary caregivers of children with a disability: A qualitative study using the Lazarus and Folkman Process of Model of Coping. *Journal of Research in Special Educational Needs*, 5(1), 3-10.

- Kenny, K., & McGilloway, S. (2007). Caring for children with learning disabilities: An exploratory study of parental strain and coping. *British Journal of Learning Disabilities*, 35(4), 221-228.
- Kersh, J., Hedvat, T. T., Hauser-Cram, P., & Warfield, M. E. (2006). The contribution of marital quality to the well-being of parents of children with developmental disabilities. *Journal of Intellectual Disability Research*, 50(12), 883-893.
- Kim, H. W., Greenberg, J. S., Seltzer, M. M., & Krauss, M. W. (2003). The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research*, 47(4/5), 313-327.
- Knussen, C., Sloper, P., Cunningham, C. C., & Turner, S. (1992). The use of the Ways of Coping (Revised) Questionnaire with parents of children with Down Syndrome. *Psychological Medicine: A Journal of Research in Psychiatry and the Allied Sciences*, 22(3), 775-786.
- Kohut, H. (2009). *The analysis of the Self: A systematic approach to the psychoanalytic treatment of narcissistic personality disorder*. Chicago: The University of Chicago press.
- Kratochwill, T. R. (1992). Single-case research design and analysis: An overview. In T. R. Kratochwill & J. R. Levin (Eds.), *Single-case research design and analysis: New directions for psychology and education* (pp. 1-14). Hillsdale: Lawrence Erlbaum Associates Publishers.
- Kromberg, J., Zwane, E., Manga, P., Venter, A., Rosen, E., & Christianson, A. (2008). Intellectual disability in the context of a South African population. *Journal of Policy and Practice in Intellectual Disabilities*, 5(2), 89-95.

- Kroodsma, L. (2008). An educational workshop for parents of children with Asperger Syndrome. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 68(12-B), 401.
- Kushlick, A., Trower, P., & Dagnan, D. (1997). Applying cognitive-behavioural approaches to the carers of people with learning disabilities who display challenging behaviour. In B. Stenfert Kroese, D. Dagnan, & K. Loumidis (Eds.), *Cognitive Behaviour Therapy for people with learning disabilities* (pp. 141-161). London: Routledge.
- Kuyken, W., Dagleish, T., & Holden, E. R. (2007). Advances in cognitive-behavioural therapy for unipolar depression. *The Canadian Journal of Psychiatry*, 52(1), 5-12.
- Kwok, H., & Cheung, P. (2007). Co-morbidity of psychiatric disorder and medical illness in people with intellectual disabilities. *Current Opinion in Psychiatry*, 20(5), 443-449.
- Lachiewicz, A., Dawson, D., Spiridigliozzi, G., Cuccaro, M., Lachiewicz, M., & McConkie-Rosell, A. (2010). Indicators of anxiety and depression in women with the fragile X premutation: assessment of a clinical sample. *Journal of Intellectual Disability Research*, 54(7), 597-610.
- Laughinghouse, J. (2010). Exploring the parenting beliefs of substance abusing women. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, 71(1-A), 349.
- Lazarus, R. S. (1999). *Stress and emotion: A new synthesis*. New York: Springer Publishing Company.
- Lee, A., & Kiemle, G. (2014). 'It's one of the hardest jobs in the world': The

- experience and understanding of qualified nurses who work with individuals diagnosed with both learning disability and personality disorder. *Journal of Applied Research in Intellectual Disabilities*. doi:10.1111/jar.12125
- Lehner-Dua, L. L. (2002). The effectiveness of Russell A. Barkley's parent training program on parents with school-aged children who have ADHD on their perceived severity ADHD, stress and sense of competence. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 62(10-B), 4792.
- Lightsey, O. R., & Sweeney, J. (2008). Meaning in life, emotion-oriented coping, generalized self-efficacy, and family cohesion as predictors of family satisfaction among mothers of children with disabilities. *The Family Journal, Counseling and Therapy for Couples and Families*, 16(3), 212-221.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Lindsay, W. R., Hogue, T., Taylor, J. L., Mooney, P., Steptoe, L., Johnston, S., . . . Smith, A. W. (2006). Two studies on the prevalence and validity of personality disorder in three forensic intellectual disability samples. *The Journal of Forensic Psychiatry & Psychology*, 17(3), 485-506.
- Liss, M., Schiffrin, H. H., & Rizzo, K. M. (2013). Maternal guilt and shame: The role of self-discrepancy and fear of negative evaluation. *Journal of Child & Family Studies*, 22(8), 1112-1119.
- Lloyd, T. J., & Hastings, R. (2009). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research*, 53(12), 957-968.

- López, J., & Crespo M. (2008). Analysis of the efficacy of a psychotherapeutic programme to improve the emotional status of caregivers of elderly dependent relatives. *Aging & Mental Health*, 12(4), 451-461.
- Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., Bishop, S. L. (2012). *Autism Diagnostic Observation Schedule* (2nd ed.) (ADOS-2). Manual (Part I): Modules 1-4. Torrance, CA: Western Psychological Services.
- Losh, M., Klusek, J., Martin, G. E., Sideris, J., Parlier, M., & Piven, J. (2012). Defining genetically meaningful language and personality traits in relatives of individuals with Fragile X syndrome and relatives of individuals with autism. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics*, 159B(6), 660-668.
- Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K., & James, W. (2007). Challenging behaviours: Prevalence and topographies. *Journal of Intellectual Disability Research*, 51(8), 625-636.
- Luck, L., Jackson, D., & Usher, K. (2007). Case study: a bridge across the paradigms. *Nursing Inquiry*, 13(2), 103-109.
- Lund, C., Kleintjes, S., Kakuma, R., & Flisher, A. J. (2010). Public sector mental health systems in South Africa: Inter-provincial comparisons and policy implications. *Social Psychiatry and Psychiatric Epidemiology*, 45(3), 393-404.
- Maes, B., Broekman, T. G., Dosen, A., & Nauts, J. (2003). Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *Journal of Intellectual Disability Research*, 47(6), 447-455.

- Mak, W. W. S., & Ho, G. S. M. (2007). Caregiving perceptions of Chinese mothers of children with intellectual disability in Hong Kong. *Journal of Applied Research in Intellectual Disabilities*, 20(2), 145-156.
- Marcinko, L., & Read, M. (2004). Cognitive therapy for schizophrenia: Treatment and dissemination. *Current Pharmaceutical Design*, 10(18), 2269-2275.
- Márquez-González, M., Losada, A., Izal, M., Pérez-Royo, G., & Montorio, I. (2007). Modification of dysfunctional thoughts about caregiving in dementia family caregivers: Description and outcomes of an intervention programme. *Aging & Mental Health*, 11(6), 616-625.
- Masasa, T., & Irwin-Carruthers, S. (2005). Knowledge of, beliefs about and attitudes to disability: Implications for health professionals. *SA Family Practice*, 47(7), 40-44.
- Matson, J. L., Neal, D., & Kozlowski, A. M. (2012). Treatments for the challenging behaviours of adults with intellectual disabilities. *Canadian Journal of Psychiatry*, 57(10), 587-592.
- May, P. A., Gossage, J. P., Brooke, L. E., Snell, C. L., Marais, A. S., Hendricks, L. S., . . . Viljoen, D. L. (2005). Maternal risk factors of Fetal Alcohol Syndrome in the Western Cape Province of South Africa: A population-based study. *American Journal of Public Health*, 95(7), 1190-1199.
- McClean, B., & Grey, I. (2012). An evaluation of an intervention sequence outline in positive behaviour support for people with autism and severe escape-motivated challenging behavior. *Journal of Intellectual & Developmental Disability*, 37(3), 209-220.

- McClintock, K., Hall, S., Oliver, C. (2003). Risk markers associated with challenging behaviours in people with intellectual disabilities: A meta-analytic study. *Journal of Intellectual Disability Research*, 47(6), 405-416.
- McConkey, R. (2005). Fair shares? Supporting families caring for adult persons with intellectual disabilities. *Journal of Intellectual Disability Research*, 49(8), 600-612.
- McCubbin, H. I., & Patterson, J. M. (1982). The family stress process: The Double ABCX Model of Adjustment and Adaption. In H. I. McCubbin, A. K. Cauble, & J. M. Patterson (Eds.), *Family stress, coping, and social support* (pp. 169-188), Springfield, IL: Haworth Press, Inc.
- McCubbin, L. (2001). *Challenges to the definition of resilience*. San Francisco, CA: American Psychological Association, University of Wisconsin-Madison. Retrieved from the ERIC database. (ED458498).
- McDonnell, A. A. (2010). *Managing aggressive behaviour in care settings: Understanding and applying low arousal approaches*. Chichester: John Wiley & Sons Ltd.
- McGill, P., Papachristoforou, E., & Cooper V. (2006). Support for family carers of children and young people with developmental disabilities and challenging behaviour. *Child: Care, Health & Development*, 32(2), 159-165.
- McGillivray, J. A., & McCabe, M. P. (2006). Emerging trends in the use of drugs to manage the challenging behaviour of people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 19(2), 163-172.
- McIntyre, L. L., Blacher, J., & Baker, B. L. (2002). Behaviour/mental health problems in young adults with intellectual disabilities: The impact on families. *Journal of Intellectual Disability Research*, 46(3), 239-249.

- McKenzie, J. A., McConkey, R., & Adnams, C. (2014). Residential facilities for adults with intellectual disability in a developing country: a case study from South Africa. *Journal of Intellectual and Developmental Disability*, 39(1), 45-54.
- McLeod, J. (2011). *Qualitative research in counseling and psychotherapy* (2nd ed.). London: Sage Publications.
- McLeod, J. (2012). *Case Study research in counselling and psychotherapy*. London: Sage Publications.
- McLeod, J., & Elliott, R. (2011). Systematic case study research: A practice-oriented introduction to building an evidence base for counselling and psychotherapy. *Counselling and Psychotherapy Research*, 11(1), 1-10.
- McStay, R. L., Trembath, D., & Dissanayake, C. (2014). Stress and family quality of life in parents of children with autism spectrum disorder: Parent gender and the double ABCX model. *Journal of Autism and Developmental Disorders*, 44(12), 3101-3118.
- McWilliams, N. (2011). *Psychoanalytic diagnosis: Understanding personality structure in the clinical process* (3rd ed.). New York, NY: The Guilford Press.
- Miklowitz, D. J., & Scott, J. (2009). Psychosocial treatments for bipolar disorder: cost-effectiveness, mediating mechanisms, and future directions. *Bipolar Disorders*, 11(Suppl. 2), 110-122.
- Mills, S., & Rose, J. (2011). The relationship between challenging behaviour, burnout and cognitive variables in staff working with people who have intellectual disabilities. *Journal of Intellectual Disability Research*, 55(9), 844-857.

- Minnes, P., Woodford, L., & Passey, J. (2007). Mediators of well-being in ageing family carers of adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disability*, 20(6), 539-552.
- Molteno, G., Molteno, C., Finchilescu, G., & Dawes, A. (2001). Behavioural and emotional problems in children with intellectual disability attending special schools in Cape Town, South Africa. *Journal of Intellectual Disability Research*, 45(6), 515-520.
- Mori, K., Ujiie, T., Smith, A., & Howlin, P. (2009). Parenting stress associated with caring for children with Asperger's syndrome or autism. *Paediatrics International*, 51(3), 364-370.
- Myrbakk, E., & Von Tetzchner, S. (2008). Psychiatric disorders and behavior problems in people with intellectual disability. *Research in Developmental Disabilities*, 29(4), 316-332.
- National Association for the Dually Diagnosed. (2007). *Diagnostic Manual – Intellectual disability: A textbook of diagnosis of mental disorders in persons with intellectual disability*. New York: NADD Press.
- Neece, C., & Baker, B. (2008). Predicting maternal parenting stress in middle childhood: the roles of child intellectual status, behaviour problems and social skills. *Journal of Intellectual Disability Research*, 52(12), 1114-1128.
- Neely-Barnes, S. L., & Dia, D. A. (2008). Families of children with disabilities: A review of literature and recommendations for interventions. *Journal of Early and Intensive Behavior Therapy*, 5(3), 93-107.
- Njenga, F. (2009). Perspectives of intellectual disability in Africa: Epidemiology and policy services for children and adults. *Current Opinion in Psychiatry*, 22(5), 457-461.

- Noble, M., Wright, G., & Cluver, L. (2006). Developing a child-focused and multidimensional model of child poverty for South Africa. *Journal of Children & Poverty, 12*(1), 39-53.
- Norizan, A., & Shamsuddin, K. (2010). Predictors of parenting stress among Malaysian mothers of children with Down syndrome. *Journal of Intellectual Disability Research, 54*(11), 992-1003.
- Oliver, C., Petty, J., Ruddick, L., & Bacarese-Hamilton, M. (2012). The association between repetitive, self-injurious behaviour and aggressive behaviour in children with severe intellectual disability. *Journal of Autism and Developmental Disorders, 42*(6), 910-919.
- Ollson, M. B., & Hwang, C. P. (2008). Socioeconomic and psychological variables as risk and protective factors for parental well-being in families of children with intellectual disabilities. *Journal of Intellectual Disability Research, 52*(12), 1102-1113.
- Osada, H., Annibal, A. C. de, Velosa, A., Poh Wan, W., Lotrakul, P., & Hara, H. (2012). Depression risks in mothers of children with developmental disabilities: A cross-cultural comparison of Brazil, Colombia, Malaysia and Thailand. *International Journal of Social Psychiatry, 59*(4), 398-400.
- Padmanabhanunni, A. (2010). *A series of systematic case studies on the treatment of rape-related PTSD in the South African context: Implications for practice and policy* (Unpublished research report for doctorate's in clinical psychology). Rhodes University: Grahamstown, South Africa.
- Palagini, L., Mosca, M., Tani, C., Gemignani, A., Mauri, M., & Bombardieri, S. (2013). Depression and systemic lupus erythematosus: A systematic review. *Lupus, 22*(5), 409-416.

- Pachankis, J. E., & Goldfried, M. R. (2007). Review article: On the next generation of process research. *Clinical Psychology Review, 27*(6), 760-768.
- Paster, A., Brandwein, D., & Walsh, J. (2009). A comparison of coping strategies used by parents of children with disabilities and parents of children without disabilities. *Research in Developmental Disabilities, 30*(6), 1337-1342.
- Patja, K., Mölsä, P., & Iivanainen, M. (2001). Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study. *Journal of Intellectual Disability Research, 45*(1), 30-40.
- Perkins, E. A., & Haley, W. E. (2010). Compound caregiving: When lifelong caregivers undertake additional caregiving roles. *Rehabilitation Psychology, 55*(4), 409-417.
- Petermann, F., & Müller, J. M. (2001). *Clinical psychology and single-case evidence: A practical approach to treatment, planning and evaluation*. Chichester: John Wiley & Sons Ltd.
- Peterson, L. Ewigman, B., & Vandiver, T. (1994). Role of parental anger in low-income women: Discipline strategy, perceptions of behaviour problems, and the need for control. *Journal of Clinical Child Psychology, 23*(4), 435-443.
- Pillay, A. L. (2012). The rape survivor with an Intellectual Disability vs. the Court. *South African Journal of Psychology, 42*(3), 312-322.
- Pillay, A. L., & Kritzinger, A. M. (2008). Psycho-legal issues surrounding the rape of children and adolescents with mental retardation. *Journal of Child and Adolescent Mental Health, 20*(2), 123-131.
- Pisula, E., & Kossakowska, Z. (2010). Sense of coherence and coping with stress among mothers and fathers of children with autism. *Journal of Autism & Developmental Disorders, 40*(12), 1485-1493.

- Plant, K. M., & Sanders, M. R. (2007). Reducing problem behavior during care-giving in families of preschool-aged children with developmental disabilities. *Research in Developmental Disabilities, 28*(4), 362-385.
- Ponterotto, J. G., Kuriakose, G., & Granovskaya, Y. (2008). Counseling and psychotherapy. In C. Willig and W. Stainton-Rogers (Eds.), *The SAGE handbook of qualitative research in psychology* (pp. 455-471).
- Power, A. (2009). 'It's the system working for the system': Carers' experiences of learning disability services in Ireland. *Health and Social Care in the Community, 17*(1), 92-98.
- Pruchno, R. A., & Meeks, S. (2004). Health-related stress, affect, and depressive symptoms experienced by caregiving mothers of adults with a developmental disability. *Psychology and Aging, 19*(3), 394-401.
- Putnam, R. (1995). Bowling alone: America's declining social capital. *Journal of Democracy, 6*(1), 65-78.
- Quinn, C. A., Rollock, D., & Vrana, S. R. (2014). A test of Spielberger's state-trait theory of anger with adolescents: Five hypotheses. *Emotion, 14*(1), 74-84.
- Ramisch, J. L., Timm, T. M., Hock, R. M., & Topor, J. A. (2013). Experiences delivering a marital intervention for couples with children with autism spectrum disorder. *The American Journal of Family Therapy, 41*(5), 376-388.
- Rapanaro, C., Bartu, A., & Lee, A. H. (2008). Perceived benefits and negative impact of challenges encountered in caring for young adults with intellectual disabilities in the transition to adulthood. *Journal of Applied Research in Intellectual Disabilities, 21*(1), 34-47.
- Reed, J. (1997). Understanding and assessing depression in people with learning disabilities. In B. Stenfert Kroese, D. Dagnan, & K. Loumidis (Eds.), *Cognitive*

Behaviour Therapy for people with learning disabilities (pp. 141-161).

London: Routledge.

Reitman, D., Currier, R. O., & Stickle, T. R. (2002). A critical evaluation of the Parenting Stress Index-Short Form (PSI-SF) in a head start population. *Journal of Clinical Child and Adolescent Psychology*, 31(3), 384-392.

Renk, K., Phares, V., & Epps, J. (1999). The relationship between parental anger and behavior problems in children and adolescents. *Journal of Family Psychology*, 13(2), 209-227.

Richman, D. M., Belmont, J. M., Kim, M., Slavin, C. B., & Hayner, A. K. (2009). Parenting stress in families of children with Cornelia de Lange syndrome and Down syndrome. *Journal of Developmental & Physical Disabilities*, 21(6), 537-553.

Roach, M. A., Orsmond, G. I., & Barratt, M. S. (1999). Mothers and fathers of children with Down Syndrome: Parental stress and involvement in childcare. *American Journal of Mental Retardation*, 104(5), 422-436.

Roberts, C., Mazzucchelli, T., Studman, L., & Sanders, M. R. (2006). Behavioural family intervention for children with developmental disabilities and behavioral problems. *Journal of Clinical Child and Adolescent Psychology*, 35(2), 180-193.

Robertson, J., Emerson, E., Hatton, C., & Yasamy, M. T. (2012). Efficacy of community-based rehabilitation for children with or at significant risk of intellectual disabilities in low- and middle-income countries: A review. *Journal of Applied Research in Intellectual Disabilities*, 25(2), 143-154.

Robertson, J., Emerson, E., Pinkney, L., Caesar, E., Felce, D., Meek, A., . . . Hallam, A. (2005). Treatment and management of challenging behaviours in

- congregate and noncongregate community-based supported accommodation. *Journal of Intellectual Disability Research*, 49(1), 63-72.
- Robertson, J., Hatton, C., Emerson, E., & Yasamy, M. T. (2012). The identification of children with, or at significant risk of, intellectual disabilities in low- and middle-income countries: A review. *Journal of Applied Research in Intellectual Disabilities*, 25(2), 99-118.
- Robson, C. (2011). *Real world research: A resource for users of social research methods in applied settings* (3rd ed.). Chichester: Wiley.
- Romeo, R., Knapp, M., Tyrer, P., Crawford, M., & Oliver-Africano, P. (2009). The treatment of challenging behaviour in intellectual disabilities: Cost-effectiveness analysis. *Journal of Intellectual Disability Research*, 53(7), 633-643.
- Roux, G., Sofronoff, K., & Sanders, M. (2013). A randomized controlled trial of group Stepping Stones Triple P: A mixed-disability trial. *Family Process*, 52(3), 411-424.
- Rowbotham, M., Cuskelly, M., & Carroll, A. (2011). Sustainable caregiving? Demands upon and resources of female carers of adults with intellectual disability. *Journal of Women & Aging*, 23(2), 129-148.
- Royal College of Psychiatrists. (2001). *DC-LD: Diagnostic criteria for psychiatric disorder for use with adults with learning disabilities/mental retardation*, (Occasional Paper OP48). London: Gaskell.
- Saloviita, T., Itälina, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A Double ABCX Model. *Journal of Intellectual Disability Research*, 47(4/5), 300-312.

- Sandy, P. T., Kgole, J. C., & Mavundla, T. R. (2013). Support needs of caregivers: case studies in South Africa. *International Nursing Review*, 60(3), 344-350.
- Scheifes, A., Stolker, J. J., Egberts, A. C. G., Nijman, H. L. I., & Heerdink, E. R. (2011). Representation of people with intellectual disabilities in randomised controlled trials on antipsychotic treatment for behavioural problems. *Journal of Intellectual Disability Research*, 55(7), 650-664.
- Schwarzer, R., & Schwarzer, C. (1996). A critical survey of coping instruments. In M. Zeidner & N. S. Endler (Eds.), *Handbook of coping* (pp. 107-132). New York: Wiley.
- Seeds, P. M., & Dozois, D. J. A. (2010). Prospective evaluation of a cognitive vulnerability-stress model for depression: The interaction of schema self-structures and negative life events. *Journal of Clinical Psychology*, 66(12), 1307-1323. doi: 10.1002/jclp.20723
- Seltzer, M. M., Almeida, D. M., Greenberg, J. S., Savla, J., Stawski, R. S., Hong, J., & Taylor, J. L. (2009). Psychosocial and biological markers of daily lives of midlife parents of children with disabilities. *Journal of Health and Social Behavior*, 50(1), 1-15.
- Seltzer, M. M., Barker, E. T., Greenberg, J. S., Hong, J., Coe, C., & Almeida, D. (2012). Differential sensitivity to life stress in *FMR1* premutation carrier mothers of children with Fragile X syndrome. *Health Psychology*, 31(5), 612-622.
- Seltzer, M. M., Floyd, F., Song, J., Greenberg, J., & Hong, J. (2011). Midlife and aging parents of adults with intellectual and developmental disabilities: Impacts of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities*, 116(6), 479-499.

- Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal on Mental Retardation*, 106(3), 265-286.
- Seltzer, M. M., Greenberg, J. S., & Krauss, M. W. (1995). A comparison of coping strategies of aging mothers of adults with mental illness or mental retardation. *Psychology and Aging*, 10(1), 64-75.
- Shah, B. M., Gupchup, G. V., Borrego, M. E., Raisch, D. W., & Knapp, K. K. (2011). Depressive symptoms in patients with type 2 diabetes mellitus: Do stress and coping matter? *Stress and Health*, 28(2), 111-122.
- Shapiro, J. R., Berkman, N. D., Brownley, K. A., Sedway, J. A., Lohr, K. N., & Bulik, C. M. (2007). Bulimia Nervosa treatment: A systematic review of randomized controlled trials. *International Journal of Eating Disorders*, 40(4), 321-336.
- Shean, G. D. (2012). Some limitations on the external validity of psychotherapy efficacy studies and suggestions for future research. *American Journal of Psychotherapy*, 66(2), 227-242.
- Shin, J. Y., & Nhan, N. V. (2009). Predictors of parenting stress among Vietnamese mothers of young children with and without cognitive delay. *Journal of Intellectual & Developmental Disability*, 34(1), 17-26.
- Silverman, D. (2013). *Doing qualitative research* (4th ed.). Los Angeles, CA: Sage Publishers.
- Silverthorn, D. U. (2007). *Human physiology: An integrated approach*. San Francisco: Pearson/Benjamin Cummings.
- Simons, H. (2009). *Case study research in practice*. London: Sage Publishers.
- Simos, G., & Hoffmann, S. G. (Eds.). (2013). *CBT for anxiety disorders: A practitioner book*. Chichester: Wiley Blackwell.

- Sinason, V. (2010). *Mental handicap and the human condition: An analytic approach to intellectual disability* (Revised ed.). London: Free Association Books.
- Singer, G. H. S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation*, 111(3), 155-169.
- Singer, G. H. S., Ethridge, B. L., & Aldana, S. I. (2007). Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: A meta-analysis. *Mental Retardation and Developmental Disabilities Research Interviews*, 13(4), 357-369.
- Singh, N. N., Lancioni, G. E., Winton, A. S. W., Singh, J., Curtis, W. J., Wahler, R. G., & McAleavey, K. M. (2007). Mindful parenting decreases aggression and increases social behavior in children with developmental disabilities. *Behavior Modification*, 31(6), 749-771.
- Skirrow, P., & Hatton, C. (2007). 'Burnout' amongst direct care workers in services for adults with intellectual disabilities: A systematic review of research findings and initial normative data. *Journal of Research in Intellectual Disabilities*, 20(2), 131-144.
- Smith, B. A., & Kaye, D. L. (2009). Treating parents of children with chronic health conditions: The role of the general psychiatrist. *The Journal of Lifelong Learning in Psychiatry*, 10(3), 255-265.
- Smith, T. B., Oliver, M. N. I., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry*, 71(2), 257-261.
- Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S. A., Irving, L. M., Sigmon, S. T., . . . Harney, P. (1991). The will and the ways: Development and validation

- of an individual-differences measure of hope. *Journal of Personality and Social Psychology*, 60(4), 570-585.
- Snyder, C. R., Simpson, S. C., Ybasco, F. C., Borders, T. R., Babyak, M. A., & Higgins, R. L. (1996). Development and validation of the State Hope Scale. *Journal of Personality and Social Psychology*, 70(2), 321-335.
- Solomon, A. H., & Chung, B. (2012). Understanding autism: How family therapists can support parents of children with autism spectrum disorders. *Family Process*, 51(2), 250-264.
- Spiegler, M. D., & Guevremont, D. C. (2003). *Contemporary behavior therapy* (4th ed.). Belmont, CA: Thompson/Watsworth
- Sprague, J., Verona, E., Kalkhoff, W., & Kilmer, A. (2011). Moderators and mediators of the stress-aggression relationship: Executive function and state anger. *Emotion*, 11(1), 61-73.
- Statistics South Africa. (2013). *Statistical release P0302: Mid-year population estimates* 2011. Retrieved from <http://beta2.statssa.gov.za/publications/P0302/P03022013.pdf>
- Stiles, W. B. (2013). The variables problem and progress in psychotherapy research. *Psychotherapy*, 50(1), 33-41.
- Stirling, A. M., Mailick, M., Greenberg, J., Warren, S. F., & Brady, N. (2013). Language dysfluencies in females with the FMR1 premutation. *Brain and Cognition*, 82(1), 84-89.
- Sturman, E. D., Mongrain, M., & Kohn, P. M. (2006). Attributional style as a predictor of hopelessness depression. *Journal of Cognitive Psychotherapy*, 20(4), 447-458.

- Sturmey, P. (2005). On some recent claims for the efficacy of cognitive therapy for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 109-117
- Sturmey, P., Laud, R. B., Cooper, C. L., Matson, J. L., & Fodstad, J. C. (2010). Challenging behaviors should not be considered depressive equivalents in individuals with intellectual disabilities. II. A replication study. *Journal of Research in Developmental Disabilities*, 31(5), 1002-1007.
- Taanila, A., Syrjäälä, L., Kokkonen, J., & Järvelin, M.-R. (2002). Coping of parents with physical and/or intellectually disabled children. *Child: Care, Health & Development*, 28(1), 73-86.
- Taylor, J. L., Novaco, R. W., Gilmer, B., & Thorne, I. (2002). Cognitive-behavioural treatment of anger intensity among offenders with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15(2), 151-165.
- Tenneij, N. H., & Koot, H. M. (2008). Incidence, types and characteristics of aggressive behaviour in treatment facilities for adults with mild intellectual disability and severe challenging behaviour. *Journal of Intellectual Disability Research*, 52(2), 114-124.
- Thackeray, L. A., & Eatough, V. (2014). 'Well the future, that is difficult': A hermeneutic phenomenological analysis exploring the maternal experience of parenting. *Journal of Applied Research in Intellectual Disabilities*.
doi:10.1111/jar.12126
- Thompson, R., Kerr, M., Glynn, M., & Linehan, C. (2014). Caring for a family member with intellectual disability and epilepsy: Practical, social and emotional perspectives. *Seizure*, 23(10), 856-863.

- Tobing, L. E. (2005). Stress, coping, and psychological distress of mothers of children with developmental disorders. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 65(12-B), 6678.
- Tonge, B, Brereton, A, Kiomall, M, MacKinnon, A., King, N., & Rinehart, N. (2006). Effects on parental mental health of an education and skills training program for parents of young children with autism: a randomized controlled trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, 45(5), 561-569.
- Totsika, V., Hastings, R. P., Emerson, E., Lancaster, G. A., & Berridge, D. M. (2011). A population-based investigation of behavioural and emotional problems and maternal mental health: Associations with autism spectrum disorder and intellectual disability. *Journal of Child Psychology and Psychiatry*, 52(1), 91-99.
- Tyrer, F., McGrother, C. W., Thorp, C. F., Donaldson, S., Bhaumik, S., Watson, J. M., & Hollin, C. (2006). Physical aggression towards others in adults with learning disabilities: Prevalence and associated factors. *Journal of Intellectual Disability Research*, 50(4), 295-304.
- Tyrer, P., Oliver, P., & Tarabi, S. A. (2014). Prevalence of aggressive challenging behaviours in intellectual disability and its relationship to personality status: Jamaican study. *Journal of Intellectual Disability Research*, 58(11), 1083-1089.
- Wall, T. N., & Hayes, J. A. (2000). Depressed clients' attributions of responsibility for the causes of and solutions to their problems. *Journal of Counseling & Development*, 78(1), 81-86.

- Watermeyer, B. (2013). *Towards a contextual psychology of disablism*. London: Routledge.
- Watermeyer, B., & Swartz, L. (2008). Conceptualising the psycho-emotional aspects of disability and impairment: The distortion of personal and psychic boundaries. *Disability & Society*, 23(6), 599-610.
- Weiner, B. (1985). An attributional theory of achievement motivation and emotion. *Psychological Review*, 92(4), 548-573.
- Wen Hung, J., Wu, Y-H., & Yeh, C. H. (2004). Comparing levels of stress of parents of children with cancer and parents of children with physical disabilities. *Psycho-Oncology*, 13(12), 898-903.
- Whitehouse, R. M., Tudway, J. A., Look, R., & Kroese, B. S. (2006). Adapting individual psychotherapy for adults with intellectual disabilities: A comparative review of the cognitive-behavioural and psychodynamic approaches. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 55-65.
- Wieland, N., & Baker, B. L. (2010). The role of marital quality and spousal support in behaviour problems of children with and without intellectual disability. *Journal of Intellectual Disability Research*, 54(7), 620-633.
- Wilkinson, R. G. (2005). *The impact of inequality: How to make sick societies healthier*. New York, NY: The New Press.
- Wilkinson, S., Joffe, H., & Yardley, L. (2004). Qualitative data collection: Interviews and focus groups. In D. F. Yardley & L. Marks (Eds.), *Research methods for clinical and health psychology* (pp. 39-55). London: SAGE Publications.
- Willig, C. (2008). *Introducing qualitative research in psychology: Advances in theory and method*. Maidenhead: Open University Press.

- Willner, P. (2005). The effectiveness of psychotherapeutic intervention for people with learning disabilities: A critical overview. *Journal of Intellectual Disability Research*, 49(1), 73-85.
- Willner, P., Jones, J., Tams, R., & Green, G. (2002). A randomized controlled trial of the efficacy of a cognitive-behavioural anger management group for clients with learning disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15(3), 224-235.
- Wodehouse, G., & McGill, P. (2009). Support for family carers of children and young people with developmental disabilities and challenging behaviour: What stops it being helpful? *Journal of Intellectual Disability Research*, 53(7), 644-653.
- Woodman, A. C., & Hauser-Cram, P. (2013). The role of coping strategies in predicting change in parenting efficacy and depressive symptoms among mothers of adolescents with developmental disabilities. *Journal of Intellectual Disability Research*, 57(6), 513-530.
- Woolfson, L., & Grant, E. (2006). Authoritative parenting and parental stress in parents of pre-school and older children with developmental disabilities. *Child: Care, Health, Development*, 32(2), 177-184.
- Woolfson, L. M., Taylor, R. J., & Mooney, L. (2010). Parental attributions of controllability as a moderator of the relationship between developmental disability and behaviour problems. *Child: Care, Health, Development*, 37(2), 184-194.
- World Bank. (2012). *South Africa economic update: focus on inequality of opportunity*. Washington, DC: Communications Development Incorporated.
- World Health Organization. (n.d.). Health topics: Mental health. Retrieved from http://www.who.int/topics/mental_health/en/

- Wright, J. H., Basco, M. R., & Thase, M. E. (Eds.). (2006). *Learning cognitive-behaviour therapy: An illustrated guide*. Washington DC: American Psychiatric Publishing, Incorporated.
- Yin, R. K. (2014). *Case Study research: Design and methods* (5th ed.). Thousand Oaks, CA: Sage Publications Inc.
- Yoong, A., & Koritsas, S. (2012). The impact of caring for adults with intellectual disability on the quality of life of parents. *Journal of Intellectual Disability Research*, 56(6), 609-619.

APPENDICES

Appendix A: The Interpretation of Maternal Experience from the Therapist's Perspective: An Epistemological and Paradigmatic Positioning of the Study

1. The Conundrum of the Researcher-Clinician in a Small Psychotherapy Study

This study has explored the caregiving experiences of a group of South African mothers. Their children accessed a specialised mental health service for adults who have intellectual disability (ID) and aggression. As described in Chapter Two of the thesis, thematic analysis was used to analyse the psychotherapy sessions and interviews. By focusing on the therapeutic process from the perspective of the therapist, this study employed a broad research agenda.

Cognitive-behaviour therapy (CBT) requires clinicians to use their training and clinical experience to conceptualise and actively interpret the psychological problems of their clients. The conceptualisation assists in treatment planning (e.g., Beck, 1995; Wright, Basco, & Thase, 2006).

My current work in a specialised clinic for adults who have ID and mental health problems sensitised me to many of the caregiving challenges that this group of South African parents face. I also refined some of these skills whilst providing clinical supervision and teaching CBT to registrars from the University of Cape Town.

The epistemological tension between my role as a clinician and researcher presented a particular dilemma: as a clinician it is considered good clinical practice to conceptualise complex family dynamics by using subjectively-acquired theoretical

knowledge and clinical experience (e.g., Beck, 1995; Kushlick, Trower, & Dagnan, 1997; Wright et al., 2006). Yet as a researcher the employment of subjective knowledge to analyse research material had the potential to produce an unacceptable degree of researcher bias, thereby reducing the series of case studies to a write-up of poorly designed anecdotal reports with limited claims to credibility and trustworthiness (Edwards, Dattilio, & Bromley, 2004; McLeod, 2011, 2012).

One example will illustrate the abovementioned epistemological conflict: In my thematic analysis I observed clinical symptoms of depression among Patricia, Linda and Hadil. Sarah was previously diagnosed with depression by a psychiatrist. As a clinician I had to interrogate the different symptoms of depression to inform treatment planning. This was done by means of various conventional open and close-ended questions, which in turn elicited linguistic responses to confirm or disconfirm whether the specific person was depressed. Importantly however, as a clinician I also had to rely on tacit non-verbal signs of possible depression such as a blunted affect and impaired information-processing as well as expressive language production because of problems with attention and concentration, which are often compromised among depressed persons (American Psychiatric Association, 2013).

The participants did not generally use psychological terminology to describe their inner psychological states and behavioural responses to stressful caregiving events. For example, Patricia certainly did not disclose in therapy that her “caregiving experiences” were influenced by “depressive symptoms such as a general sense of helplessness and prominent apprehensive expectations that were linked with generalised anxiety”. I used my knowledge of clinical psychology to interpret

Patricia's repeated descriptions of anxiety and depression. I also observed distressed non-verbal behaviour.

As a psychotherapist I was not unaffected by my professional engagement with the participants of this study. This holds true especially when they recalled painful or traumatic experiences (Gibson & Swartz, 2001; Hollway & Jefferson, 2013; McWilliams, 2011; Ponterotto, Kuriakose, & Granovskaya, 2008). Far from being objective, my active engagement in the psychotherapy process with participants invariably activated my personal ideas, feelings, cultural perceptions and self-beliefs about their life experiences (e.g., Gibson & Swartz, 2001). I may or may not have been aware of my subjectivity in the moment of therapy, but the subjectivity of myself as a psychotherapist and those in therapy were tangibly present when meaning was collaboratively sought (Gibson & Swartz, 2001; Hollway & Jefferson, 2013; Ponterotto et al., 2008).

In this study, my attempts to describe the caregiving experiences of a group of mothers could represent my own opinions, interpretations, misinterpretations and values of caregiving if my subjective interpretations were uncritically written-up and left unchecked by external sources (Edwards et al., 2004; Eells, 2007; McLeod, 2011, 2012; Silverman, 2013; Yin 2014).

This writing covers theoretical and epistemological aspects of researcher-subjectivity to generate scientific knowledge. More specifically, I will focus on epistemological paradigms regarding subjectivity and the interpretation of the experiences of participants from the perspective of the researcher in this psychotherapy study.

I described the strategies that were employed to enhance the study's credibility and trustworthiness in Chapter Two: First, the provision of long narratives with over 130 quotations allowed readers to check the credibility of my write-up and observations of the therapeutic process against their own knowledge-base and clinical experience. Second, an external party counted the number of omissions and additions in a selection of written transcripts to ensure that the research material accurately reflected the audio-recordings. Third, as I will describe at the end of this writing, peer supervision was employed to externally evaluate the codes and themes that I identified in the study.

Credibility and trustworthiness were therefore enhanced by employing an external examiner who interrogated the themes against her own interpretations and engagement with the research material. The research material was also made available to another examiner with experience in the field of ID. He assessed whether the themes were credible although this process did not take the form of intense peer supervision and researcher reflexivity.

Even though I employed recommended strategies to enhance qualitative rigour in this study, the mere incorporation of such strategies will not be enough to make the research product credible and trustworthy. I also need to demonstrate *how* I enhanced the credibility of this study through the use of peer supervision and other strategies to enhance rigour - the reader needs to form an opinion whether I made a credible effort to enhance the study's credibility.

As described in the last chapter of my thesis, I am aware of the numerous limitations of the study and legitimate concerns about methodological design. By providing a

detailed account of the theoretical factors that informed this study's underlying epistemological framework, I hope to demonstrate that this study was based on a credible research design that was informed by sound and legitimate epistemological considerations.

By describing the level of my engagement with epistemological theory and the strategies that were used to make my interpretations more credible, I hope to show that I did not produce case reports that were based on unthoughtful or anecdotal clinician-researcher observations. Besides the limited scientific value of such work, on an epistemological level the use of non-reflected researcher subjectivity to describe maternal experiences would objectify the participants of this study in a rather blatantly disrespectful and unacceptable manner.

2. The Unavoidability of Researcher Subjectivity when Investigating Complex Social and Behavioural Phenomena

2.1 Introduction

Social scientific research cannot be conducted without attempts to interpret the material that is produced (Hollway, 2015; Hollway & Jefferson, 2013; Ponterotto et al., 2008). All data, whether obtained through statistical quantification or qualitative analysis, are grounded in the subjectivity of the researcher. In fact, as I will demonstrate in the next section, all data are by necessity *contaminated* by the researcher (Hollway & Jefferson, 2013; Ponterotto et al., 2008).

2.2 Researcher subjectivity in quantitative research: An example from survey research

Survey research could be defined as an empirical method that aims to measure discrete human experiences, often by attaching a relative value to the intensity or frequency of specific constructs (Hollway & Jefferson, 2013).

Hollway and Jefferson (2013) used a British crime survey to illustrate that researcher-subjectivity is unavoidable. The survey asked the question: "How safe do you feel walking alone in this area after dark?" (p. 6). Hollway and Jefferson (2013) noted that *"survey research interviews of this kind, where answers can be quantified on a Likert scale, are so prevalent that their capacity to produce evidence is taken for granted"* (p. 7).

The survey used sound statistical methods to establish adequate reliability and validity. Hollway and Jefferson (2013) critically assessed the subjectivity of the researchers who had constructed the survey by asking the following questions:

- How and why did the researchers decide to associate darkness with safety; and fear with darkness?
- Is a perception of "unsafety" speaking to fear or anxiety?
- How often do the highly urbanised British walk in the dark of night? Would it not be more common or typical for pedestrians to walk under the street lights of British cities? And how often would they walk alone, unaccompanied by friends or relatives? Conversely, what images did the potentially-threatening, solitary, nocturnal strolls evoke among participants? Does such imagery not resemble the type of fictional scenes that tend to be portrayed in popular

horror movies? To what extent was this question then measuring what the authors *assumed* it measured?

- With subsequent claims by the researchers that elderly women were more fearful about crime than younger men, how would the perceptions of these participants differ from younger males? As Hollway and Jefferson (2013) argue: "For young men, it might suggest fighting; for older people, mugging; for women, sexual assault" (p.7). What exactly then is meant by crime?
- The researchers assumed that fear was a constant state when activated by specific prerequisites, i.e., a dark night and a sense of isolation. What impact would contextual factors have on the manifestation of fear, anxiety or threat through the course of time?

2.3 The study of experience from the perspective of participants: The use of bracketing in qualitative research

The qualitative research paradigm represents a wide range of research approaches from different epistemological positions. In broad terms, the different schools within social qualitative research reject the possibility of researcher objectivity across personal, cultural, linguistic and professional domains (Hollway & Jefferson, 2013; Wertheimer, 2011; Yardley & Marks, 2004). Of course, the unobtainability of objectivity in qualitative social research does not preclude the necessity of using strategies to enhance the credibility and trustworthiness of the research product.

Bracketing is a widely-used qualitative research strategy to enhance rigour in semi-structured interviews, focus groups and other qualitative material collection methods. Bracketing could be defined as a "scientific process in which a researcher suspends or holds in abeyance his or her presuppositions, biases, assumptions, theories, or

previous experiences to see and describe the phenomenon" (Gearing, 2004, as cited in Tufford & Newman, 2012, p. 82).

Bracketing originated from phenomenology. The method is especially useful when qualitative research attempts to describe the experiences of participants as they were reported and described (Brinkman, Jacobsen, & Kristiansen, 2014).

Interpretative phenomenological analysis (IPA) is a more contemporary research method that maintains the central idea of delivering a research project from the point of view of the participants. However, IPA recognises the role of the researcher as attempting to "interpret the sense-making of participants" (Pringle, Drummond, McLafferty, & Hendry, 2011, p. 21). IPA strives to deliver in-depth insight into the experiences of participants. Yet the co-construction of meaning between researcher and participant is overtly acknowledged; and researchers are encouraged to analyse the expressed opinions and views of participants. The use of excerpts and quotations is promoted to firmly ground interpretations in the experience of participants from their own perspective (Pringle et al., 2011).

The valuable contributions of psychological research that has focused on the experiences of participants from their own perspective cannot be overstated. It has given voice and agency to the recipients of psychological interventions, often comprising marginalised and vulnerable persons (Tufford & Newman, 2012).

The underlying epistemology of strategies such as bracketing holds language as the medium to capture the experience of participants (Brinkman et al., 2014; Hollway, 2015; Hollway & Jefferson, 2013).

According to Hollway and Jefferson (2013), the idea that language would facilitate a credible understanding of the participant's experience from her own perspective is based on ". . . (an) assumption (that) relies on a discredited theory of the transparency of language" (p. 9). Hollway (2015) argues that researchers would then need to assume that participants have sufficient self-knowledge and skills to more or less accurately verbalise and disclose their experiences to a relative stranger (Hollway & Jefferson, 2013).

Proponents of post-structuralism and deconstruction would argue that the participant and researcher could have different interpretations about the meaning of the same word or phrase (Frie, 2003a).

In many forms of qualitative research, the subjective opinions, views, knowledge and assumptions of the researcher have a direct bearing on the selection and choice of questions in interviews and focus groups, and the manner in which responses are subsequently interpreted (Hollway & Jefferson, 2013).

3. Paradigmatic clashes regarding the use of the researcher's knowledge, opinions and experiences to generate knowledge and facilitate understanding

In light of the meaningful and empowering contributions of studies that focused on experience from the perspective of participants, this writing will now focus on whether this study should have used specific methods to bracket my subjective opinions, knowledge, beliefs and experience. It would have been an acceptable and empirically-sound strategy to use semi-structured interviews before, during and after psychotherapy with the six participants. Moreover, the interviews could have been used to provide a platform for participants to describe their caregiving experiences

and their perceptions regarding the use of psychotherapy (e.g., McLeod, 2011, 2012).

In such a design, thematic analysis would have been used to describe the experiences of the participants in a manner that closely reflected the texts that they generated. It is conceivable that the risk of producing anecdotal reports would have been effectively mitigated if my analysis was firmly focused on the direct verbal descriptions of interviewees in response to open-ended questions (Silverman, 2013). This study has described many distressing aspects of caregiving and maternal experiences that were disclosed in psychotherapy. As described earlier, the analysis of findings was done from the perspective of myself as psychotherapist and researcher.

Positivist criticism would raise legitimate questions about the validity of findings and the risk of producing anecdotal reports that are based on my (potentially) prejudiced opinions and assumptions (e.g., Edwards et al., 2004; McLeod, 2011).

With a distinctly different approach, contemporary psychodynamic epistemology has also eschewed the writing-up of research that lacks the required mechanisms to account for the assumptions and experiences of the researcher:

- In psychodynamic terms, the researcher's unconscious processes such as motivation and compensations would have an impact on the process of psychotherapy and the analysis of research material (e.g., Hollway, 2015; Hollway & Jefferson, 2013).
- If I am a defended subject, my unconscious motivations, projections and intellectualisations may inform the analysis of data in a fundamental manner.

The credibility and trustworthiness of findings could be legitimately queried if interpretations rest more on my own complexes, emotions and issues than the co-constructed experiences of participants (e.g., Hollway, 2015; Hollway & Jefferson, 2013).

- From a CBT perspective, it is conceivable that my own automatic thoughts would be activated when analysing research material. In this case my subjective interpretation of the text could cast doubt on the credibility and trustworthiness of findings. For example, hypothetically, during psychotherapy I might have had the following negative automatic distortion in the form of an imperative:

A mother must be able to keep her emotions in control when her child becomes aggressive; it is her own fault if the child acts out.

A careful exploration of my hypothetical belief would suggest that I was minimising the severity of the child's behaviour and the emotional impact of such behaviour on the mother. The imperative thinking that informs an expectation that mothers *should* somehow be able to control their emotions is also entrenched in a broad and vague understanding of control. If only things were that easy!

In order to firmly justify the analysis methods that were employed in this study, I need to briefly engage in some of the complex epistemological discourses that are at play in psychotherapy research. The following points resonate firmly with my epistemology of psychotherapy research:

- As described earlier, language is a crucial but imperfect hermeneutic vehicle. The researcher's subjective engagement with participants may result in

(unconscious) bias if he has different connotations and meanings from the participants with regard to the words that were used during interviews (Hollway, 2015; Hollway & Jefferson, 2013).

- The unconscious processes (formulated psychodynamically) of clients/participants in psychotherapy, or at least beliefs and motivations that they are unaware of (when conceptualised from CBT-perspective), could create distance between their expressed opinions and latent defences or cognitive distortions: their experiences could therefore involve much more than what is expressed through language (e.g., Beck, 1995; Hollway, 2015; McWilliams, 2011).
- The focus on descriptive experiences “as they were told” could in such instances be enriched by the theoretical knowledge and clinical experience of the clinician-researcher. Moreover, the researcher may, through his subjective and co-constructed engagement with the research material, shed light on the ambivalent or defended half-truths, distorted cognitions and latent material that participants disclosed (Edwards et al., 2004; Hollway, 2015; Hollway & Jefferson, 2013; Yardley & Marks, 2004).
- Empirical efforts to reduce subjectivity to the greatest extent possible might prevent researchers from accessing a potentially valuable instrument that could be used to generate knowledge about complex human phenomena: the subjectively-obtained clinical knowledge of the researcher (Frie, 2003b; Hollway & Jefferson, 2013).

4. The Use of Reflexivity to Monitor the Researcher's Experiences, Opinions and Assumptions

Reflexivity could be used to improve the quality of analysis; researcher reflexivity furthermore provides a valuable research method to avoid grossly inaccurate interpretations or unconscious personal bias (Hollway & Jefferson, 2013; McLeod, 2011, 2012).

Reflexivity could be defined as a process in which the researcher is actively engaged in efforts to understand his own feelings, thoughts and behaviours when conducting research (Frosh & Young, 2008; Hollway & Jefferson, 2013; McLeod, 2011). In turn, reflexivity is inseparable from the theoretical and experiential context that the researcher employs to make sense of data (Frosh & Young, 2008). Frosh and Young (2008) understood reflexivity as the researcher's use of his subjectivity to construct knowledge of the participant's experiences:

Subjectivity is viewed by psychoanalysis, as with much qualitative research, not as a problem but as a resource (and topic). To draw upon one's own subjectivity in the research process does not mean that one is not being "objective", but that one actually comes closer to a truer account. In psychoanalytic terms, the "investment" the researcher has in the material they are studying plays a major role in the interest that will eventually accrue from the research. (p. 113)

The schism between positivist research methods that aim to reduce researcher bias and the use of reflexivity as a constructionist enhancement of truthfulness and data-related trustworthiness is of central importance to this study. As described in Chapter Two, methodological rigour was enhanced through the use of reflexivity. I

did not try to subvert my subjectivity to enhance rigour by bracketing my interpretation of events within psychotherapy during analysis.

Instead, I met regularly with my supervisors to discuss the credibility of the themes that were identified. As described, the use of peer supervision took the form of intensive discussion of the text and the credibility of findings. Another psychotherapist perused the written research material. During these processes we were critical and mindful of the role of my beliefs, feelings and behaviour. In peer supervision, we also engaged with the role of our respective personal backgrounds, training and clinical experience on the analysis of the research material.

It follows that the use of researcher subjectivity in this study would be at least partly justified, with subsequent claims to enhanced credibility, once another clinician arrived at similar thematic outcomes after she had perused the research material (Hollway, 2015; Hollway & Jefferson, 2013).

Recognition of the claims that have been made so far would inform the rest of this writing: if we accept the supposition that complete objectivity in research is unobtainable, the question remains as to how reflexivity could be used to access the knowledge, opinions and experiences of the researcher when analysing the research material (as opposed to a perhaps oversimplified conceptualisation of subjectivity as an unwanted product that should be controlled).

5. An Epistemological Match Between Researcher Reflexivity and Psychotherapy

As described at the onset of this writing, psychodynamic therapy and cognitive-behaviour therapy emphasise the central importance of the therapist's self-awareness or conscious reflection about his own feelings or beliefs when he is engaged with clients; both approaches also require clinicians to actively use their subjectivity to formulate or conceptualise case presentations (e.g., Beck, 1995; McWilliams, 2011).

In psychodynamic therapy, countertransference feelings and reactions are used to obtain insight into the inner lives of clients, and it informs the process of psychotherapy (e.g., McWilliams, 2011). In cognitive-behaviour therapy, authoritative practitioners, such as Judith Beck, have urged psychotherapists to constantly monitor their own automatic beliefs and possible cognitive distortions about themselves as therapists; they should also gauge their reactions when working with clients with specific problems such as personality disorder (Beck, 1995).

By acknowledging the active role of subjective awareness and introspection in both psychotherapeutic approaches, an emphasis on the role of reflexivity in psychotherapy research will reflect similar processes of self-awareness and self-reflection (Hollway, 2015; Hollway & Jefferson, 2013).

An epistemological acknowledgement of the researcher's subjectivity as a potential research tool would link conventional psychotherapy practice with the use of reflexivity in research (Edwards et al., 2004; Eells, 2007; McLeod, 2011, 2012). In this regard, psychotherapists are trained and sensitive to the fundamental influence

of their own perceptions and feelings within the psychotherapy space (Hollway, 2015; Hollway & Jefferson, 2013; Kohut, 2009; Ponterotto et al., 2008).

This writing thus far has attempted to highlight epistemological complexity and the lack of a perfect, clear-cut methodological answer from the respective post-positivist and constructionist paradigms. In order to describe some of the epistemological assumptions that I employed in this study, a brief statement is necessary to distinguish broadly between positivism and constructionism.

6. Towards Positioning the Study's Focus on Maternal Experiences within Existing Paradigmatic Discourses: The Positivist-Constructionist Debate in Psychotherapy Research

The space limitations that were set for this thesis prevented an extensive discussion about the core ontological and epistemological differences between positivism and social-constructionism in psychotherapy research. It is also important to note that both epistemological positions, and interloping positions between them, are represented in qualitative research and mixed-methods designs, which results in paradigmatic clashes about the manner in which subjectivity should be harnessed or controlled in qualitative research (Hollway, 2015; Hollway & Jefferson, 2013; McLeod, 2011; Spencer, Pryce, & Walsh, 2014; Willig & Stainton-Rogers, 2008).

Positivist or realist research paradigms have dominated psychological research since the inception of experimental laboratories by Wilhelm Wundt in the 1870s (e.g., Wertheimer, 2011). A classical positivist research paradigm would assert that objective knowledge of human beings could be obtained through observation and the employment of scientific methods (Yardley & Marks, 2004; Wertheimer, 2011; Willig & Stainton-Rogers, 2008).

Classical positivism contends that objective knowledge is achievable through the use of statistical methods to reduce researcher bias and the impact of spurious variables on the relationship between independent and dependent variables; validity and reliability scales allow inferences to larger populations and the repeated measurement of constructs over time (Golafshani, 2004; Hayes, 2000; Hill, Chui, & Baumann, 2013; Yardley & Marks, 2004).

Within postmodernism, social constructionism has denounced the radical and positivist epistemological assumptions that are hinged on the existence of an absolute, objective, internal and rational mind (McLeod, 2011; Yardley & Marks, 2004)

As opposed to the control of researcher bias, proponents of the more extreme forms of postmodernism have questioned and rejected the reification of an independent Cartesian mind that operates in *isolated independence* within a person's body (Frederickson, 2003; Frie, 2003b; Yardley & Marks, 2004).

Social constructionism considers the relational aspects of psychotherapy as cornerstones of meaning-making and the generation of knowledge: meaning is jointly constructed between therapist and client because of their relatedness and *being* with each other. Their historical context, linguistic background, cultural beliefs and practices are cardinal influences on an essentially social process of meaning-making. Knowledge-generation is therefore generally considered to be externally organised between people (Frie, 2003b; Watermeyer, 2013; Willig, 2008).

From a social-constructionist perspective in qualitative research, researchers and participants are interactive contributors to knowledge-generation. While there are many different qualitative research methods to analyse research material, a general

observation of qualitative inquiry would acknowledge the importance of recursive linguistic interpretations as units of analysis (Brinkman et al., 2014; Elliot, Fischer, & Rennie, 1999; Guba & Lincoln, 1994; Hill et al., 2013; Spencer et al., 2014; Willig, 2008).

Social research seldom subscribes to purist research methodologies that strictly adhere to either radical positivism or the more extreme approaches within social-constructionism (Guba & Lincoln, 1994). Although a study's underlying epistemological position could most often be traced back to broader indices of positivism or social-constructionism, interposing positions between the two approaches are common (Guba & Lincoln, 1994; Yardley & Marks, 2004).

To use one or two examples, a qualitative researcher could support the use of positivism to investigate natural-scientific phenomena; and qualitative researchers could also acknowledge the existence of a possible objective and external truth/reality without discarding the central importance of socially-constructed meaning in social sciences. Content analysis represents a qualitative method that uses numbers to make sense of research material (Yardley & Marks, 2004).

On the other hand, researchers with a mainly post-positivist orientation may consider it impossible to achieve objective results within the social sciences because of the complexity of behaviour. Yet the empirical and nomothetic methods to enhance validity and reliability could simultaneously be valued as (flawed) mechanisms to further scientific knowledge about multi-layered human processes (Yardley & Marks, 2004).

7. Research from the Therapist's Perspective: A Critical Appraisal of the Study's Focus on Maternal Experiences from Epistemological Positions within Positivism and Social Constructionism

I described the research methodology that was employed in this study in Chapter Two. From a post-positivist view, it is conceivable that a researcher may be able to access some of the internal thought processes and emotions of participating subjects through rigorous empirical strategies aimed at minimising researcher bias (e.g., McLeod, 2012). Researchers in the positivist and post-positivist schools will however strongly reject claims of statistical validity and reliability in a small study such as this one (e.g., Kazdin, 2007).

The decision to explore maternal experiences from the perspective of the therapist could be legitimately criticised from an extreme position within social-constructionism: First, if meaning is socially-constructed and shared *between* two persons, interpretive knowledge-claims that are seemingly hinged on the analysis of subjective experiences *within* another person could be legitimately refuted (Frie, 2003b; Gendlin, 2003). Stated differently, if knowledge is generated through the context of my relation with participants, our being-in-the-world-with-each-other, theoretical vantage points that attempt to locate their experiences as reified internal realities are essentially flawed (Frie, 2003b; Gendlin, 2003).

Last, even if I could stake my claim that experiential knowledge exists subjectively within the internal organising structures of participating mothers, it remains their experiences, not mine. My subjective assumptions, knowledge, potential bias and different experiences will therefore prevent an analysis of the subjective experience of another person (Cannon, 1991, 2003; Frie, 2003b).

Social constructionism would argue that the participant and I are *trapped* in our postmodern subjectivity: our different understandings of the world are founded on our respective cultural and historical experiences and our different language backgrounds. My engagement in psychotherapy and the concomitant research efforts to adduce truthful or credible accounts of maternal experiences could therefore be criticised and dismissed as artefacts of my own subjectivity, that is, in the event in which I had not made a concerted effort to bracket researcher subjectivity (Cannon, 1991, 2003; Frie, 2003a).

In addition, at the more extreme end of social-constructionism, the writing-up of maternal experiences by a therapist could be understood as a process of objectifying the participant (Cannon, 1991, 1993; Frie, 2003b). As opposed to acknowledging the complex reality of shared experience, research from the therapist's perspective (as the subject or observer) about the clients' experiences (as objects being observed) could be criticised as mechanistic and simplistic (Frie, 2003b).

In this scenario the criticism is directed against what is perceived as my efforts to separate myself from participants in a Cartesian and natural-scientific manner, to objectify participants by describing and subverting reified maternal experiences into discrete themes, thereby missing the point of social constructions and intersubjectivity completely (Frie, 2003b).

8. Reflections on My Efforts to Explore Maternal Experiences in the Context of Psychotherapy: Epistemological Assumptions and a Response to Social-Constructionist and Post-Positivist Criticism

The positivist-social constructionist debate represents a complex and contentious paradigmatic clash in psychotherapy research (Yardley & Marks, 2004). As a psychotherapist and clinical psychologist, I appreciate the important contributions of realist/positivist and social-constructionist research approaches in psychotherapy and clinical psychology.

Randomised Controlled Trials did not receive accolades from the scientific world and policy makers undeservedly, and its contributions to social scientific knowledge and progress cannot be overstated: by establishing rigorous evidence for the efficacy of various psychotherapeutic approaches across different therapeutic modalities, RCTs increased the standing of psychotherapy research in the scientific community (Kazdin, 2007; Shean, 2012); as the most authoritative research design in efficacy studies, clinicians also obtained information about the broad outcomes of treatment, which could then be critically and pragmatically disseminated against existing conceptual clinical frameworks that might result in improved patient-care (Edwards, 2007; Edwards et al., 2004; Kazdin, 2007).

I am also appreciative of social-constructionism and its understanding of psychotherapy as a complex interpersonal process involving the shared experience or joint construction of meaning between two or more people (Gendlin, 2003). Meaning ensues in the dynamic interaction between us and our joint efforts to make sense of experiences both past and immediately present (Frie, 2003b).

As described earlier, a reductionist and more radical form of social constructionism would at a minimum eschew research methodology that is not embedded in the concept of shared experience. It could be argued that this position represents an underlying ontology that places or constructs meaning outside the person. Such a perspective would contend that there is neither subject nor object in psychotherapy research; ideas regarding the self as part of an individual, organising and rational mind are therefore overthrown in favour of inter-subjectivity or social constructions (Frie, 2003b).

Does this mean self-experience do not exist? Within the context of psychotherapy, I would like to briefly discuss European existential-phenomenology to defend my epistemological position. Their writing began shaping my epistemology long before I started this research project. My argument will not detract from the valid emphasis that social constructionism has placed on the inter-subjective space in psychotherapy. Instead, I will argue that the maternal experiences I wrote about in this study went over and beyond the more extreme and reductionist claims within social constructionism which relates to a *purely* external or socially-constructed organisation of experience (Frederickson, 2003; Frie, 2003b). As I will describe, the role of self-experience, both my self-experience and the self-experience of participants, enabled the generation of meaning and knowledge (Frederickson, 2003).

9. Existential-Phenomenological Approaches to Understanding Experience within the Context of Psychotherapy

9.1 Introduction

Each of the European or Continental existential-phenomenological philosophers developed sophisticated theories of human experience (Frie, 2003b; Sousa, 2005). Because of the limited space available, I will primarily focus on basic existential-phenomenological principles that relate to the present psychotherapy study. A brief description of fundamental ideas in existential-phenomenology will solely aim to ground my argument that it is possible for clinician-researchers to write about the experiences of their clients/study participants.

Because the study's use of the term caregiving *experience* rested on an underlying epistemological understanding that is based on existential-phenomenology, a brief statement is required to clarify its inclusion in the research question.

9.2 Applying an existential-phenomenological understanding of experience to the present study

Thompson (2003) based his description of the word *experience*, as it translates into English in the Oxford Dictionary's definition, as a person's capacity to ". . . feel, suffer and undergo, in the sense that what we experience is not of our own making" (p. 201). He also claimed that the word *experience* could be substituted in the English language with related concepts such as experiment and empirical. Experience therefore tends to signify a degree of external organisation, empiricism and the possible use of the scientific method (Thompson, 2003).

With its roots firmly embedded in some of the Western-European languages, the meaning of the word *experience* in existential-phenomenological approaches is based on the German bifurcation of the English word into two related concepts: *Erfahrung* and *Erlebnis* (Thompson, 2003). *Erfahrung* refers to a journey over time; *zu fahren*, which the existential-phenomenologists understood as an accumulation of experiences. *Erlebnis* refers to an immediate and momentary experience, *zu leben*, to live (Cilesiz, 2011; Thompson, 2003).

The distinction between *Erfahrung* and *Erlebnis* resonates with my linguistic background and understanding of the word *experience*. In Afrikaans and Dutch the concept translates into two words that have obvious phonetic and semantic resemblance to the German words: *ervaring* and *belewenis/belevenis*.

The existential-phenomenological understanding of experience therefore incorporates the accumulation of knowledge-acquisition through *Erfahrungen* and its experiential expression in the immediate moment. Crucially, experience is therefore conceptualised as being organised within the internal and external structures of the person (Thompson, 2003).

The present study adopted the existential-phenomenological use of the word *experience* in the following manner:

Caregiving experiences represented the participating mothers' world of experience. They shared some of their caregiving experiences with me in psychotherapy and during interviews; their ideas were conveyed through the use of language when they used their agency from self-experience to express their ideas, assumptions and feelings about different events in their lives and the impact it had on them.

By reflecting on Erfahrungen or their journey of experience in the psychotherapy space, their world of experience simultaneously included and surpassed the act of disclosing caregiving experiences in the immediacy of the psychotherapeutic moment (Erlebnis). Erfahrung also signified a parental journey and the acquisition of beliefs and assumptions about parenting via their engagement with their children over the course of time.

I wrote about their caregiving experiences from the perspective of the therapist, i.e., through my self-experience (which includes my training and knowledge about psychology) of the research process and shared experience with participants.

At times, I became aware of co-constructed content that was experienced by a participant, although she was not always aware of the experience.

I will use two examples to further illustrate how caregiving experiences were conceptualised in this study:

If a child became physically aggressive towards his mother in the course of the week leading up to psychotherapy, the parent often disclosed distressing aspects about the episode in therapy. She held beliefs about the meaning of aggression as it pertains to her child; and she simultaneously reported emotions such as shame, anger, embarrassment and disappointment (self-experience disclosed through dialogue). Her beliefs and emotional experiences were present in therapy, but also based on past experiences which included her role as parent, her child's aggression, etc. Mothers often named their beliefs and emotions spontaneously during dialogue, or in response to my questions (a co-constructed process). At other times I wrote about my observations of latent material, e.g., if Linda became tearful at different intervals of intervention, I used my subjective-self experience to postulate that she

may be sad about something. The participants signified the meaning of their experiences either directly through language (participant self-experience) or meaning was derived from tacit information that I observed and interpreted in our relationship (researcher self-experience).

Last, consider a participant's response to the question: "What happened since we last saw each other?" The question might have elicited the following response: "I feel sad and angry because my child lashed out at me." In this context, I was able to code "maternal anger and sadness because of the child's behavioural difficulties" directly from maternal descriptions of such phenomena during psychotherapy.

As part of the psychotherapy process we also wanted to alleviate distressing aspects of their caregiving experiences. The participants were able to answer questions, sometimes change their behaviour; they also at times disagreed with me through the process of mutual engagement. They had shown the ability to reflect on discussion, to critically appraise my questioning and non-verbal prompts.

I do not agree with the epistemological premise that a person must verbally express their experience to make it legitimately their own. This premise is based on the following assumptions from the researcher: First, that the participant must be aware of her experience, which implies different levels of mindfulness. Second, that language, a cognitive function, must be used to share that experience.

9.3 Experience, existential-phenomenology and psychotherapy research: The therapist-researcher and participants as embodied entities in lived experience

Existential-phenomenological philosophy has rejected overly-simplified mechanistic and reductionist scientific research methods to explain complex human behaviour in psychological research (Brinkmann et al., 2014; Frie, 2003b; Hickey & Mireia, 2012; Sousa, 2005).

Brinkmann and colleagues (2014) have defined phenomenology as "the study of *phenomena*—in other words, of the world as it appears to experiencing and acting human beings" (p. 22). Phenomenology describes human experience as mostly conscious events. The German philosopher Edmund Husserl is generally credited as the creator of the phenomenological method (Frie, 2003b). However, his conceptualisation of consciousness through a "transcendental ego" remained grounded in Descartes's ideas of a rational mind that could be separated from the rest of the body (Frie, 2003b; Orange, 2001).

Existential-phenomenology grew out of phenomenology and represents a group of thinkers, each with their own theoretical underpinnings. As with earlier phenomenological thinking, existential-phenomenology attempts to make sense of human experience. Unlike the earlier work by Husserl, existential-phenomenologists developed different theoretical constructs that have rejected the idea that consciousness experience could be explained through a Husserlian distinction between body and mind (Frie, 2003b).

Existential-phenomenological philosophers sought to describe consciousness "not from the 'inside-out', as is the case in classical psychoanalytic theory of unconscious intrapersonal defences, but from the perspective of lived experience" (Frie, 2003b,

p.14). Existential-phenomenological thinkers such as Martin Heidegger, Maurice Merleau-Ponty, Jean-Paul Sartre and Martin Buber had a profound influence on subsequent developments in social constructionism (Cannon, 2003; Chamberlain, Camic, & Yardley, 2004; Frederickson, 2003; Frie, 2003b; Gendlin, 2003)

Contemporary existential-phenomenological discourses regarding psychoanalysis and psychotherapy have also questioned the inherent reductionism of the more radical approaches within social constructionism and postmodernism (Frederickson, 2003; Frie, 2003b). By arguing that meaning is essentially organised by external and social processes within psychotherapy and research, between therapist and client, reductionist social constructionists leave little room for the internal organising aspects of the individual client-participant (Frederickson, 2003; Frie, 2003b).

From an existential-phenomenological perspective, the dilemma with this argument is that therapeutic change, i.e., an individual client-participant's changes in terms of behaviour, feelings and cognitions, are not adequately and singularly accounted for by the *external* social relationship as conceptualised within radical social constructionism (Frie, 2003b). By implication, relational and external processes would then resort outside the individual control of both client and therapist (Frederickson, 2003; Frie, 2003b; Mills, 2003).

If the postmodernist argument concerning the denial of therapist and/or clients as subjects is true, we will be unable to explain the client's capacity to act and change distressing aspects of her lived experience (Mills, 2003). If psychotherapy involves the treatment of psychological problems, it is implied that clients *do* something about their psychological problems, often outside demarcated psychotherapy sessions (Frie, 2003b). This resonates with CBT's emphasis on homework assignments and

the application of restructured beliefs in the person's living environment (e.g., Beck, 1995).

Radical proponents of social constructionism criticise any psychotherapy research as Cartesian if it is not based on inter-subjective meaning-making: unless research is grounded in co-constructed processes of external knowledge-generation, clinician-researchers would mistakenly hold the participants as objects, thereby subscribing to Cartesian solipsism, i.e., a reality that only exists through the internal experiences of a reified mind that is separate from everything else (Frederickson, 2003; Frie, 2003b; Skirk, 2014).

Contemporary existential-phenomenological thinkers have responded by laying down the following suppositions of psychotherapy process (Cannon, 2003; Frederickson, 2003; Frie, 2003b; Gendlin, 2003; Mills, 2003; Skirk, 2014; Sousa, 2005):

- As with social-constructionism, existential-phenomenology firmly rejects the idea of a rational, mechanistic and independent mind that is separated from bodily experience and the world surrounding a person.
- As with social-constructionism, meaning-making occurs through social processes and the influence of the therapist and client's own histories, culture and linguistic backgrounds or language.
- However, unlike reductionist forms of social constructionism, the internal processes of human experience (self-experience) and the client/participant-as-a-subject are also acknowledged and interrogated.
- Existential-phenomenology reconceptualised a person's internal meaning-making processes against the Cartesian traditions of a body-mind split as

representing a *dynamic* and *interactive* process between a person's internal organisation and co-construction with another.

- Internal processes and experiences are therefore continuously shaped by a person's interaction with others *and* their self-experience of language, culture and history.

The abovementioned suppositions can now be applied to the current psychotherapy study in the following ways:

- Each participant and the clinician-researcher are subjects in a dynamic therapeutic relationship that is characterised by shared experience. Just as I am holding the participant in mind during our interaction, the participant holds me in mind (Cannon, 2003).
- The internal world of each participant is not conceptualised as an entirely independent and self-organised Cartesian object (Frie, 2003b).
- Instead, participants possess a degree of internal agency and the freedom to choose how they position themselves within the relationship; psychotherapy is experienced as their *being-in-the-moment-with-another* (Frederickson, 2003; Frie, 2003b).
- Each participant-as-subject has the freedom and responsibility to act and change behaviours where required. There is a degree of internal self-organisation within each person, allowing her to reflect on her self-experience in the co-constructed space of therapy (Cannon, 2003; Frederickson, 2003).
- Each participant uses her agency and potential to become authentic to her self-experience that is inseparable from her language background, personal history and cultural embeddedness (e.g., Gabriel, 2013; Thompson, 2003).

- Likewise, the therapist-researcher is not unaffected by his subjective self-experience, which was used to make sense of the co-constructed research material that emerged from interviews and psychotherapy sessions (Frie, 2003b).

Without exception, existential-phenomenological thinkers have conceptualised experience as a phenomenon that is simultaneously co-constructed and internally organised by the person's engagement with another (Frie, 2003b). Because of the study's focus on caregiving experiences as disclosed in the psychotherapy space, I will briefly describe how experience as a dynamic interaction between external and internal organisation was formulated:

Heidegger described his central idea of experience as a person's "*Dasein*" or "Being-in-the-world". *Dasein* was not conceptualised as a duality between interpersonal relationships and self-organisation through an internal self (Mills, 2003). Heidegger proposed that self-experience could be achieved through the realisation of authenticity, i.e., the process of becoming aware of our nature by reflecting and exploring our existence and distinctiveness (Hickes & Mirea, 2012; Mills, 2003). Heidegger's distinction between "Being-with" another person (*Mitwelt*), "Being-in" the world (*Umwelt*) and "Being-with-the-private-self" (*Eigenwelt*) speaks to complex interactive processes that transcend being as a purely relational phenomenon (Hickes & Mirea, 2012; Frie, 2003a).

Merleau-Ponty emphasised an embodied experience in which the person engages with another to move-forward-in-the-moment (Gendlin, 2003). Meaning is derived from the whole body's continuous positioning within the present here-and-now, albeit

with a *preconscious* understanding of the material evoked by our continuous perceptual awareness (Frie, 2003a; Gendlin, 2003).

Sartre explicated the fundamental idea of becoming conscious of one self through the eyes of another, a phenomenon he referred to as "The Look". Again, although social engagement with another is emphasised, in an expansive and complex commentary of ontology Sartre also acknowledged the existence of an internal "preconscious reflection" and a "reflected consciousness" (Cannon, 2003). The latter critically appraises preconscious reflection as an object; whereas prereflective consciousness is simply self-consciousness.

Thus, a person has the capacity to evaluate his self-consciousness in a reflective manner. If a person becomes aware of herself, i.e., obtain self-consciousness, for example as observed through the eyes of another, that person has the capacity to reflect on the phenomenon of self-experience (preconscious reflection) as being embarrassing, empowering, pleasant, untenable, etc. (reflected consciousness) (Cannon, 2003).

10. "Their Parental Stress Belongs to Them": Do I Objectify Participants by Writing-Up their Experiences from my Relational Position as the Researcher?

Contemporary existential-phenomenologists and psychoanalytic researchers would argue that it is not only possible but desirable for researchers to interpret the experiences of participants (e.g., Frosh & Young, 2008; Hollway, 2015; Frie, 2003a). The existential-phenomenological field simultaneously rejects claims that analysis in research and therapy could result in findings that represent an absolute or objective truth (Frie, 2003a; Frederickson, 2003; Hensen, 2007; Thompson, 2003). Heidegger

wrote extensively about truth and untruth as a means to understand experience; and his writings also influenced subsequent deconstructionist perspectives regarding difference (Frie, 2003a).

It is not only important to understand why I interpreted the caregiving experiences of participants, but also how those experiences were analysed. This statement does not refer to methodology, but rather the act of understanding, the hermeneutics behind my efforts to interpret research material.

An epistemological recognition of the dynamic interaction between the self-experience of the researcher-therapist and those from the participants in the co-constructed space of therapy represents a very different paradigmatic position from one where participants are objectified. Psychotherapy is a specific relationship that explicitly acknowledges the psychological embeddedness of the therapist. An epistemology of research which recognises that interpretation should go beyond what was said in therapy to harness the knowledge of the therapist finds a natural synchrony with the psychotherapy method (Hollway, 2015).

Frie (2003b) argued that the personal meaning of psychotherapy to clients emerges from their engagement through self-experience. A considerable part of this meaningful engagement would be lost if knowledge was generated purely through inter-subjective constructions.

My professional contributions to our shared dialogue had the potential to actively assist or discourage clients from making sense of their experiences. As a therapist I

had to co-create adequate opportunities for clients to make sense of caregiving experiences on a personal level in the psychotherapy space (Strong & Zeman, 2005).

As a researcher, I was not given *carte blanche* to interpret the research material by producing non-reflexive descriptions and analyses that were exclusively based on my subjective impulses. As described in Chapter Two, the analysis of research material incorporated recommended qualitative strategies aimed at enhancing rigour, e.g., credibility and generalisability. Besides the other strategies, the use of peer supervision is a legitimate psychotherapy case study method to enhance external credibility (e.g., Edwards et al., 2004; Hollway, 2015, 2016; Hollway & Jefferson, 2013).

11. The Use of Peer Supervision as an External Form of Credibility

11.1 Emerging codes and themes that were derived directly from dialogue and the verbal descriptions of participants

The codes and themes that emerged from thematic analysis were drawn from the verbal descriptions of participants during psychotherapy sessions and interviews. I mostly used open-ended questions to cover collaboratively-set agenda points during co-constructed psychotherapy sessions. Consistent with the CBT model, the participating mothers were encouraged to fully explore the meaning of emerging content: they elaborated on their own statements; asked me questions to assist with clarifying some of their thoughts and feelings; or responded to questions I asked about specific beliefs, behaviours, emotions or contextual interpersonal and social issues.

When I recursively analysed the transcripts to identify codes and themes, I tried to stay close to the participant's direct verbal descriptions of different maternal experiences. For example, when Patricia described her reaction to Sue's demanding and re-assurance seeking behaviours as becoming "so angry that I wanted to hit her head off her face" I coded maternal anger as a consequence of the child's behavioural difficulties. Patricia identified feelings of anger, sadness and resentment about other behavioural incidents involving Sue, e.g., her daughter's insistence that her brother-in-law should fix his DVD player; the demand to visit a restaurant to eat out; demands to repeat lists of family members who were visiting over the Easter Weekend; and when Sue demanded that Patricia got up from her bed to skip a track on one of Sue's favourite CDs, given Sue's dislike for the specific song.

Patricia also described feelings of anger towards Sue when her daughter displayed demanding behaviour and verbal aggression. The coding of maternal anger because of the child's behaviour was repeated on different occasions across various sessions.

11.2 The use of psychological knowledge and the interpretation of latent verbal and non-verbal signifiers

Even though language is widely recognised as an imperfect, incomplete and at times inaccurate signifying system, research interviews frequently rely exclusively on the analysis of a participant's verbal responses to analyse research material (Hollway, 2015, 2016).

As Hollway (2015) has pointed out, the subjective interpretations of a researcher with acquired expertise and specialised knowledge could potentially provide considerable insight and generate relevant knowledge in clinical research. In this context,

researcher subjectivity does not only refer to potential prejudice and bias, but also to clinical knowing through training and experience. This is particularly the case in complex clinical studies and psychotherapy research that deal with intricate psychological and social phenomena (Hollway, 2015). Participants may also struggle to accurately express their experiences with the use of language if such experiences are confounded by psychodynamic defences, cognitive distortions, possible emotional disengagement or avoidant behaviours (e.g., Beck, 1995; Hollway, 2015; Hollway & Jefferson, 2013; McWilliams, 2011).

11.3 Peer supervision

The research material was made available to the person who participated with me in peer supervision. The material included the audio-recordings, written transcripts, thematic analysis, narratives of sessions and the writing-up of each case study.

I had peer supervision with a registered clinical psychologist and psychotherapist, Dr Charlotte Capri. Charlotte holds PhDs in Clinical Psychology and Political Science. She works as a psychologist and psychotherapist in the intellectual disability field and has recently published peer-reviewed journal articles about aspects of caregiving in the South African context. The reference list of the thesis includes an article citation of a recent paper written by her and published in the *Journal of Applied Research in Intellectual Disabilities*. Charlotte was trained in CBT and psychodynamic therapy.

Spanning over fourteen hours of discussion, Charlotte and I interrogated the themes that were identified in this study:

- First, Charlotte independently analysed the case studies of Patricia and Sarah before our meetings took place to conduct an analysis and identify themes from her own perspective. We decided to identify these two case studies because I perceived the work with Sarah and Patricia as the most challenging; the two participants also continued to experience high levels of parental stress after therapy was completed.
- Second, Charlotte studied the research material of the remaining four case studies. We discussed each case study in length and Charlotte provided feedback about the credibility of the themes that I identified from her perspective. During discussion Charlotte also commented on her own observations about the four remaining cases.
- Last, peer supervision became a co-constructed space in which we unpacked the meaning of convergent and divergent themes by reflecting on similar observations or divergent interpretations.

a) Patricia:

We agreed before the onset of peer supervision that Charlotte would not code emerging themes through a psychodynamic lens, but rather pay close attention to the material from a CBT perspective. The credibility of diagnoses was also placed high on the agenda.

- As a general observation that was applicable to all of the cases, Charlotte told me that she felt the participants had "too much to deal with"; their experiences were "too much to manage". Her resulting countertransference was one of pronounced helplessness, which resonated with my own sense of feeling

overwhelmed by many of the parental reports at various intervals of intervention.

- Charlotte's independent analysis of Patricia's case study highlighted symptoms of severe major depression and generalised anxiety. She noted Patricia's repeated descriptions of nervousness and restlessness. Charlotte described the birthday party of Patricia's grandson as a typical example of a relatively minor event that led to prominent features of anxiety, including apprehension, social avoidance, and physiological symptoms (nausea and vomiting).
- With regard to depressive symptoms, Charlotte was struck by the severity of Patricia's helplessness and hopelessness. She also commented that Patricia's helplessness appeared to have evolved "*over a very long time*", and made links with earlier formative parenting experiences. She described Patricia's presenting problems as "*protracted*". Her observations resonated with my descriptions that Patricia was "*stuck in a rut*".
- Charlotte noted that Patricia's parental stress was ranked slightly lower towards the end of intervention.
- She observed that Patricia often avoided conflict in her relationships with others, including her husband, immediate family and relatives. Traits of social avoidance were also noted, and Charlotte postulated that the pervasive nature of social avoidance might allude to persistent traits across different relationships.
- Charlotte identified the following possible core beliefs:
 - I am vulnerable.
 - I cannot be helped.

- I am inadequate.
- Patricia's reference to being "*a people's pleaser*" was linked with non-assertiveness towards other family members. Charlotte noted that Patricia's relationship with her husband and children were characterised by "*discontent*" – Patricia was overtly unwilling to be continue having her other children take up so much of her time. Being a people's pleaser, Patricia was unable to use her agency to voice her frustration about her children's dependence on her and her husband's management of Sue's behaviour, i.e., his willingness to humour Sue to Patricia's detriment. Charlotte also picked up that Patricia experienced ambiguity towards her husband's assistance in managing Sue's behaviour: at times she became annoyed with him only to voice her appreciation for his support soon after negative comments were made.

Following discussion, we agreed that Charlotte's observations of Patricia's discontent and self-description as a "*people's pleaser*" resonated with my descriptions of Patricia's non-assertiveness and the family tension within their household. Charlotte also described the role of Patricia's husband in managing Sue's behaviour as constituting a "*maddening double-bind*" to Patricia: either accept Peter's efforts to pacify Sue by giving in to unreasonable demands, or deal with the consequences if Sue acted out when her father did not engage in efforts to "*keep the peace*".

- Consistent with my observations, Charlotte linked Patricia's parental stress to Sue's behavioural difficulties. Besides generalised anxiety, Charlotte described the possibility of trauma, i.e., that Patricia was traumatised by the severity of Sue's behavioural outbursts and her earlier parental experiences regarding epilepsy.

By and large, Charlotte's independent analysis converged with the themes that emerged from the analysis that I conducted. The two points of divergence were Charlotte's emphasis on possible trauma and Patricia's persistent avoidance as a means of coping with social stressors. With regard to the former, Charlotte perceived Patricia's ongoing sense of danger, i.e., when Sue threatened her or acted out, as possible indications of trauma. She also linked perceptions of danger with apprehensive expectations that were part of generalised anxiety.

Insofar as avoidant behaviour towards social stressors is concerned, I partially covered the concept as a broader coping strategy to deal with Sue's behaviour. I did not, however, use avoidant coping as a strategy to deal with stressful aspects within different interpersonal and family relationships. Following reflection, I eventually decided to not include trauma as a diagnostic label because so many of the symptoms were accounted for by generalised anxiety. I incorporated Patricia's ambivalence towards her family into the narratives and analysis. I decided to include brief comments that would explicitly link Patricia's non-assertiveness towards family and relatives with the coping strategy of avoidance.

Discussion also clarified two additional themes that I identified: First, I had observed persistent feelings of anger in Patricia; and she also reported feelings of anger as a response to stressful caregiving and family events. Secondly, I described incidents where Patricia's parental stress was linked with her son, for example when Patricia started worrying that her son was smoking marijuana. Charlotte agreed that both themes were present in the research material. She grouped this theme under the theme that was related to a sense of discontent towards other family members. She also recognised Patricia's anger, and linked it as one of the emotional consequences of extreme helplessness.

b) Sarah:

Charlotte identified two broad themes in this case study:

- Sarah experienced a social disability that was especially evident in her interaction with Ethan. Charlotte referred to this theme as *"dually disabled communication and social disability"*. Charlotte also believed that Sarah's social insight was significantly impaired as a result, which led to her difficulties in managing Ethan's behaviour and the *"socially-maladaptive"* manner in which they related as mother and child.

Charlotte identified high levels of helplessness and hopelessness in Sarah because of her pervasive communication and social difficulties. This was also linked with her parental stress because Sarah found it difficult to comprehend her role in Ethan's behavioural difficulties, i.e., that the conflict between them resulted in Ethan's acting out.

Charlotte contended that Sarah's problems with communication and social interaction most likely had a negative impact on her relationship with her other children.

- As a second theme, Charlotte identified persistent financial stressors and ongoing concerns about the financial implications of Ethan's care. Sarah's concerns about money matters extended towards her other family members. Charlotte also observed Sarah's tendency to list moneys owed to her by family members. She believed that Sarah may feel embarrassed and ashamed about her financial difficulties, which she then attributed to the prohibitive cost of looking after Ethan.

On the whole, Charlotte's themes converged with the themes that I identified. Her conceptualisation of Sarah's autism as representing a social disability and the

"socially-maladaptive" relationship between Sarah and Ethan is in keeping with the dysfunctional parent-child relationship that I described. Furthermore, Charlotte's observations regarding Sarah's helplessness to manage Ethan's behaviour related to my observations of Sarah's parental stress as the result of Ethan's behaviour and her difficulties with social interaction as well as communication. When I asked Charlotte about her views regarding Sarah's presentation of anger, which she did not identify thematically, Charlotte told me that she believed *"Sarah was very angry about many things in her life."* She conceptually traced it back to a form of dissonance in which Sarah struggled to understand why her children and people at church were unsupportive. Moreover, Sarah struggled to comprehend why her children were not supporting her with Ethan if she assisted them with money.

11.4 The remaining case studies: The use of peer supervision to enhance the credibility of the study

Charlotte stated that she found the themes of the remaining cases credible and trustworthy. She told me that she found the descriptions regarding earlier parental experiences as formative influences of contemporary maternal beliefs, emotions and behaviours particularly useful.

She noted positive improvements with regard to high levels of parental stress and/or depressive symptoms as reflected by test scores and verbal feedback among Linda, Hadil, Marlene and Jeanette. Against this, Charlotte agreed that Patricia and Sarah experienced little therapeutic gain with regard to parental stress, although she felt Patricia's sense of helplessness became less pronounced.

- Besides the written transcripts, Charlotte listened to some of the audio-recordings of my work with Linda. We also listened to some of the excerpts in supervision.

Based on Linda's accounts of events and the manner in which it was presented, i.e., Linda's tone of voice, pitch and prosody, Charlotte noted high levels of anger and interpersonal conflict across different social relationships. She also identified Linda's core beliefs as being unlovable, defective and inadequate. Charlotte thought that Linda's decision to admit Tony to hospital activated a sense of being a bad parent and a bad person. Having forsaken care on a temporary basis, Charlotte thought that Linda might have simultaneously experienced a sense of relief and guilt for feeling relieved. Negative automatic thoughts about abandoning care activated similar beliefs which led to feelings of guilt and shame. Likewise, Charlotte noted that Linda's conflictual relationship with her husband persisted over the course of three decades. Notwithstanding the reported disintegration, Linda's decision to remain in the marriage was seen as being possibly linked with fears regarding abandonment.

Other observations regarding Linda included the following:

- The presence of severe depression at the onset of intervention and improvement of depressive symptoms as therapy progressed.
- Anger towards Tony and homicidal ideation combined with expressed needs to discontinue caregiving.
- The longitudinal presence of depressive symptoms, anger, interpersonal conflict and unstable relationships with significant others over the course of time. Charlotte confirmed that the personality traits that I described were tangibly evident whilst she was perusing through the material.
- Charlotte noted that the inclusion of socio-economic context was important and relevant to the current study. She also commented that the extent of resource

scarcity and financial strain, especially among the participants who live in relative poverty, may be difficult to fully grasp for readers that were unfamiliar with the immediate South African context.

We discussed Linda's old car as an example of how unreliable transport could potentially have serious downstream ramifications that add to the participants' experience of strain and stress. Linda presented with significant financial strain and relative poverty. When she attended psychotherapy after hours, on more than one occasion Linda voiced her concerns about her old and increasingly unreliable Ford. There were no trains or bus routes close to the family's small holding; and the last trains on the Eastern Line completed their journey before 21:00. These rides were generally considered as unreliable and unsafe. Her journey back home also took her past some areas of town with high rates of violent crime. Linda's attendance to psychotherapy, and indeed my own presence, posed an element of personal risk to both of us. Then there were also numerous break-ins into their house and Linda's unwillingness to leave Kim or Tony unsupervised at home, fearing for their safety. In this context, Linda's worry about financial strain and the possibility that she might not be able to afford petrol could have a broader impact than just transport problems.

We also discussed the relevance of vocational placement problems if the child had behavioural difficulties, and that none of the children were able to use public transport on their own because of safety concerns. Likewise, Patricia's fear of being assaulted at home by burglars, Hadil's experience of being held at gun point after one of our sessions, the break-in at their house, and Jeanette's recollection of the time that Cindy was raped all had a bearing on their general levels of psychological stress.

Charlotte also recognised the role of other social stressors and the impact of negative family events on parental coping resources. We discussed Jeanette and Marlene's experience of intimate partner violence, the tension between Hadil and her eldest son, and the substance dependence among family members of Linda and Jeanette as prominent family stressors. We furthermore discussed some of the chronic physical health concerns that some of the parents reported, and concluded that some of the parents directly referred to the negative role of chronic health conditions in caregiving. Examples include Patricia's descriptions that she cannot assist family members, including Sue, with many of their activities of daily living because of her arthritis and emphysema; Sarah's fear and worry that her arthritis makes her vulnerable to get hurt when Ethan is aggressive; and Hadil's reports of chronic insomnia that caused day time drowsiness, which in turn had a reported negative impact on her ability to attend to all her caregiving tasks.

- As a point that was closely related to the previous statement, Charlotte also observed that the parental stress of all the participants were at times caused by children that did not have intellectual disability. However, all the participants experienced elevated parental stress as a result of the behavioural difficulties of their children who had ID.
- Charlotte agreed with my observations and Marlene's self-reports that most of her parental stress was the result of her conflict with Leon. In this regard, Charlotte noted Marlene's reported anger and guilt towards Leon. Charlotte described unfinished business with Leon's father, Marlene's first husband, in the following manner: *"It seems as if she (Marlene) is trying to resolve issues with Leon Senior through Leon Junior."*

When we discussed this in more detail, Charlotte explained that she experienced Marlene as being rather conflicted in her relationship with her eldest son: On the one hand, she became increasingly assertive towards Leon, but she would often retract her assertiveness by becoming more conceding. Charlotte conceptualised Marlene's conceding behaviour towards her son as the result of a history of intimate partner violence.

I described Marlene's increasing assertiveness towards Leon in the narratives; I also made links between intimate partner violence and an abusive former marriage as formative influences to Marlene's management of conflict with especially Leon. Moreover, when prompted, Marlene realised that Leon reminded her of her abusive husband during times of conflict.

In a way, Charlotte took this theme one step further by postulating that unprocessed remnants of the physical, emotional and sexual abuse continued to linger in Marlene's mind when she confronted Leon. While she was becoming increasingly assertive towards him, it is conceivable that Marlene's experience of IPV might have led to feelings of fear that escalating conflict with her son might result in verbal or physical abuse. On a behavioural level, it would then be possible that Marlene responded with worrying thoughts and fearful feelings by becoming less assertive and more conceding. I incorporated Charlotte's conceptual thinking of Marlene as moving between confrontation and appeasement into Marlene's case study.

- Similar to my own observations, Charlotte believed that some of Hadil's anger might have been related to a growing sense of dissonance: while Hadil took full responsibility for being the primary caregiver of her children, her numerous references of inadequate, unsympathetic or inappropriate family support

suggested an underlying expectation that her family should be more supportive. Charlotte got the sense that she was increasingly dissatisfied and angry about this state of affairs. Similar to my observations, Charlotte also thought that Hadil's conflict with her eldest son signified a degree of discontent that could likewise be traced back to her role as caregiver – it is possible that she felt unappreciated and disrespected when describing how much she did for him, especially because of the rude, dismissive and abrupt manner in which he reportedly treated her.

- Charlotte recognised the enormity of Hadil's challenges in providing caregiving to three children with disability as a central theme. She also linked Hadil's ongoing dissonance and unhappiness with positive earlier formative influences.

To be more specific, Charlotte saw Hadil's relative happy early childhood memories with reference to her family of origin as Hadil's ideal standard against which she continued to measure her family's challenges which contributed to her own unhappiness.

Likewise, Hadil's perceptions that she was not a good mother, with subsequent feelings of guilt and shame, were weighted against her own mother's good mothering. Charlotte also saw the break-up of Hadil's former engagement with her husband's brother as a significant formative event that shaped core beliefs regarding being "*at fault*". More specifically, her brother-in-law's warning that her children would be disabled was internalised in an almost superstitious way: she continued to feel guilty about her children's disability, thinking that she was somehow to blame. On a concrete level, her decision to break the engagement altered the course of her life.

We discussed Hadil's caregiving challenges in detail and Charlotte again commented that it felt that Hadil must have felt overwhelmed by having to persistently deal with the compounded caregiving challenges of her three children. Similar to my own experiences at the time of therapy, Charlotte also described a countertransference of helplessness and hopelessness. Following discussion, we agreed that our countertransference was meaningful, i.e., that it perhaps resembled some of Hadil's perceptions. In this regard, I should add that Hadil directly described a sense of helplessness to deal with caregiving demands during different intervals of intervention.

REFERENCES

- American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Beck, J. S. (1995). *Cognitive therapy: Basics and beyond*. New York, NY: The Guilford Press.
- Brinkmann, S., Jacobsen, M. H., & Kristiansen, S. (2014). Historical overview of qualitative research in the social sciences. In P. Leavy (Ed.), *The Oxford handbook of qualitative research* (pp. 17-42). Oxford: Oxford University Press.
- Cannon, B. (1991). *Sartre and psychoanalysis: An existential challenge to clinical metatheory*. Lawrence, KS: University Press of Kansas.
- Cannon, B. (2003). Sartre's contribution to psychoanalysis. In R. Frie (Ed.), *Understanding experience: Psychotherapy and postmodernism* (pp. 27-51). London: Routledge.
- Chamberlain, K., Camic, P., Yardley, L. (2004). Qualitative analysis of experience: Grounded theory and case studies. In D. F. Marks & L. Yardley (Eds.), *Research methods for clinical and health psychology* (pp. 69-89). London: Sage Publications Limited.
- Cilesiz, S. (2011). A phenomenological approach to experiences with technology: Current state, promise, and future directions for research. *Educational Technology Research and Development*, 59(4), 487-510.
- Edwards, D. J. A. (2007). Collaborative versus adversarial stances in scientific discourse: Implications for the role of systematic case studies in the development of evidence-based practice in psychotherapy. *Pragmatic Case Studies in Psychotherapy*, 3(1), 6-34.

- Edwards, D. J. A., Dattilio, F. M., & Bromley, D. B. (2004). Developing evidence-based practice: The role of case-based research. *Professional Psychology: Research and Practice*, 35(6), 589-597.
- Eells, T. D. (2007). Generating and generalizing knowledge about psychotherapy from pragmatic case studies. *Pragmatic Case Studies in Psychotherapy*, 3(1), 35-54.
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38(3), 215-229.
- Frederickson, J. (2003). The eclipse of the person in psychoanalysis. In R. Frie (Ed.), *Understanding experience: Psychotherapy and postmodernism* (pp. 204-224). London: Routledge.
- Frie, R. (2003a). Language and subjectivity: From Binswanger to Lacan. In R. Frie (Ed.), *Understanding experience: Psychotherapy and postmodernism* (pp. 137-160). London: Routledge.
- Frie, R. (2003b). Introduction: Between modernism and postmodernism: Rethinking psychological agency. In R. Frie (Ed.), *Understanding experience: Psychotherapy and postmodernism* (pp. 1-26). London: Routledge.
- Frosh, S., & Saville-Young, L. (2008). Psychoanalytic approaches to qualitative psychology. In W. Stainton Rogers & C. Willig (Eds.), *Handbook of qualitative research in psychology* (pp. 109-126). London: Sage Publishers.
- Gabriel, G. (2013). Roads of freedom – An existential-phenomenological approach to a psychotherapy journey. *Existential Analysis*, 24(1), 95-105.

- Gendlin, E. (2003). Beyond postmodernism: From concepts through experiencing. In R. Frie (Ed.), *Understanding experience: Psychotherapy and postmodernism* (pp. 100-115). London: Routledge.
- Gibson, K., & Swartz, L. (2001). Psychology, social transition and organizational life in South Africa: "I can't change the past - but I can try". *Psychoanalytic Studies*, 3 (3/4), 381-392.
- Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, 8(4), 597-607.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage.
- Hayes, N. (2000). *Doing psychological research: Gathering and analysing data*. Maidenhead: Open University Press.
- Hensen, M. (2007). On experience and psychotherapy: A dialogue with Michel de Montaigne. *Existential Analysis*, 18(1), 70-80.
- Hickes, M., & Mirea, D. (2012). Cognitive behavioural therapy and existential-phenomenological psychotherapy: Rival paradigms or fertile ground for therapeutic synthesis? *Existential Analysis*, 23(1), 15-31.
- Hill, C. E., Chui, H., & Baumann, E. (2013). Revisiting and re-envisioning the outcome problem in psychotherapy: An argument to include individualized and qualitative measurement. *Psychotherapy*, 50(1), 68-76.
- Hollway, W. (2015). Knowing mothers: *Researching maternal identity change*. New York, NY: Palgrave MacMillan.
- Hollway, W. (2016). Emotional experience plus reflection: Countertransference and reflexivity in research. *The Psychotherapist*, 62, 19-21.

- Hollway, W., & Jefferson, T. (2013). *Doing qualitative research differently: A psychosocial approach* (2nd ed.). London: Sage Publishers Limited.
- Kazdin, A. E. (2007). Evidence-based treatment and practice: New opportunities to bridge clinical research and practice, enhance the knowledge base, and improve patient care. *American Psychologist*, 63(3), 146-159.
- Kohut, H. (2009). *The analysis of the Self: A systematic approach to the psychoanalytic treatment of narcissistic personality disorder*. Chicago, IL: The University of Chicago press.
- Kushlick, A., Trower, P., & Dagnan, D. (1997). Applying cognitive-behavioural approaches to the carers of people with learning disabilities who display challenging behaviour. In B. Stenfert Kroese, D. Dagnan, & K. Loumidis (Eds.), *Cognitive Behaviour Therapy for people with learning disabilities* (pp. 141-161). London: Routledge.
- McLeod, J. (2011). *Qualitative research in counseling and psychotherapy* (2nd ed.). London: Sage Publications.
- McLeod, J. (2012). *Case Study research in counselling and psychotherapy*. London: Sage Publications.
- McWilliams, N. (2011). *Psychoanalytic diagnosis: Understanding personality structure in the clinical process* (3rd ed.). New York, NY: The Guilford Press.
- Mills, J. (2003). A phenomenology of becoming: Reflections on authenticity. In R. Frie (Ed.), *Understanding experience: Psychotherapy and postmodernism* (pp. 116-136). London: Routledge.
- Orange, D. (2001). From Cartesian minds to experiential worlds in psychoanalysis. *Psychoanalytic Psychology*, 18, 287-302.

- Ponterotto, J. G., Kuriakose, G., & Granovskaya, Y. (2008). Counseling and Psychotherapy. In C. Willig & W. Stainton-Rogers (Eds.), *The SAGE handbook of qualitative research in psychology* (pp. 455-471).
- Pringle, J., Drummond, J., McLafferty, E., & Hendry, C. (2011). Interpretative phenomenological analysis: a discussion and critique. *Nurse Researcher*, 18(3), 20-24.
- Shean, G. D. (2012). Some limitations on the external validity of psychotherapy efficacy studies and suggestions for future research. *American Journal of Psychotherapy*, 66(2), 227-242.
- Silverman, D. (2013). *Doing qualitative research* (4th ed.). Los Angeles, CA: Sage Publishers.
- Skirk, C. (2014). Existential-phenomenology and the conceptual problem of other minds. *The Southern Journal of Philosophy*, 52(2), 227-249.
- Sousa, D. (2005). The world of the text and existential-phenomenological psychotherapy. *Existential Analysis*, 16(2), 248-268.
- Spencer, R., Pryce, J., & Walsh, J. M. (2014). Philosophical approaches to qualitative research. In P. Leavy (Ed.), *The Oxford handbook of qualitative research* (pp. 81-98). Oxford: Oxford University Press.
- Strong, T., & Zeman, D. (2005). 'Othering' and 'selving' in therapeutic dialogue. *European Journal of Psychotherapy, Counselling and Health*, 7(4), 245-261.
- Thompson, M. G. (2003). The primacy of experience in R. D. Laing's approach to psychoanalysis. In R. Frie (Ed.), *Understanding experience: Psychotherapy and postmodernism* (pp. 180-203).
- Tufford, L., & Newman, P. (2012). Bracketing in qualitative research. *Qualitative Social Work*, 11(1), 80-96.

- Watermeyer, B. (2013). *Towards a contextual psychology of disablism*. London: Routledge.
- Wertheimer, M. (2011). *A brief history of psychology* (5th ed.). New York: Psychology Press.
- Willig, C. (2008). *Introducing qualitative research in psychology: Advances in theory and method*. Maidenhead: Open University Press.
- Willig, C., & Stainton-Rogers, W. (2008). Introduction. In C. Willig & W. Stainton-Rogers (Eds.), *The SAGE handbook of qualitative research in psychology* (pp. 1-12). London: Sage Publications Limited.
- Wright, J. H., Basco, M. R., & Thase, M. E. (Eds.). (2006). *Learning cognitive-behaviour therapy: An illustrated guide*. Washington DC: American Psychiatric Publishing, Incorporated.
- Yardley, D. F., & Marks, L. (2004). Introduction to research methods in clinical and health psychology. In D. F. Yardley & L. Marks (Eds.), *Research Methods for Clinical and Health Psychology* (pp. 1-20). London: Sage Publications.
- Yin, R. K. (2014). *Case Study research: Design and methods* (5th ed.). Thousand Oaks, CA: Sage Publications Inc.

Appendix B: Consent Form to Participate in Research – Mothers



Department of Psychiatry and Mental Health

University of Cape Town

J-Block, Groote Schuur Hospital

CONSENT TO PARTICIPATE IN A RESEARCH PROJECT

The name of the research project: *Parenting stress and inadequate coping: An exploration of the use of cognitive-behaviour therapy with mothers whose adult children have intellectual disability and aggressive behaviour**

Dear Participant

You are being asked to participate in a research project. My name is Ockert Coetzee and I'm a psychologist working at Alexandra Hospital. I would like to do research with mothers of children with intellectual disability and behavioural problems. It includes adult children.

Earlier studies have shown that mothers of children with intellectual disability do most of the caregiving which includes help in daily tasks and medical appointments. When children have behavioural problems, especially aggression, it often becomes very difficult and stressful for mothers to look after their child. For this reason, the study will use a form of therapy called psychotherapy, which is also called talking-therapy to help deal with stresses and worry that are often experienced when looking after an adult child who has intellectual disability and behavioural problems.

The study will take place at Alexandra Hospital and 5 mothers will participate in the study. Alexandra is the only specialised centre for adults with intellectual disability and psychiatric problems in the Western Cape. Because the study uses psychotherapy, only a few mothers participate. With the exception of one research group after therapy is completed, individual participation implies mostly one to one work with myself.

PROCEDURE

If you decide to take part in the study, consent will be obtained from you and your child. The study explores the experience of stress among mothers. This is very much linked with your child's behaviour and your thoughts and feelings about being a parent. We shall therefore attempt to get consent from your child by explaining in appropriate, basic ways what the study is about. It follows that your child's level of understanding will inform us if it is possible to describe the process to him or her. Following your consent the following will take place:

The study is scheduled to take place from January 2012 to January 2013. First, during a one to one interview I shall ask questions about your experiences as a parent and some of the caregiving challenges you've had to deal with through the years. Second, we'll use of number of tests to measure parenting stress, burnout and caregiving responsibilities and how you deal with them. We shall also measure how intense and severe your child's behavioural problems are. These tests take approximately 2 hours to administer. Third, psychotherapy sessions will take place weekly over a period of one or two months, which means that you'll have to visit Alexandra regularly. We can increase sessions to 2 sessions

weekly if you have that time. Fourth, after we've finished psychotherapy the same tests described before will be repeated. Fifth, a 1 hour after you've finished psychotherapy will give you the opportunity to describe your experience as a participant in the study. Sixth, with your permission, assessment is repeated 4 months after we've completed psychotherapy. The same tests are used at different times of the study to find out if psychotherapy changes the things the tests measure. Finally, a group with other mothers will be facilitated by another psychologist to allow you to share with the group how you experienced psychotherapy and other parts of the study. Leaving out the final tests 4 months after therapy and the focus group at the end of research are completed, your involvement in the study will stretch over a period of 1 – 2 months.

Should you choose to have your child supervised during the time, a registered psychiatric nurse is available to look after your child whilst you participate in the study. We'll have a variety of meaningful, recreational activities that consider your child's interests, hobbies and level of ability.

Please note that you may choose to withdraw from the study at any time. A decision to withdraw will have no impact on access to future services. All the services at Alexandra Hospital will still be available and withdrawing from the study will not have any impact on your use of services.

AUDIO-RECORDING AND CONFIDENTIALITY

We also request permission to make tape-recordings of the interviews, administration of tests and psychotherapy. Recordings will be used strictly for the study as memory aid, i.e., to assist in remembering what was said during psychotherapy and the interviews. Research is conducted anonymously, implying that your name will not be disclosed during any part of the research process. Audio-recordings, tests, psychotherapy and interview notes will be stored in a secure location only accessible to the researcher. Your name will be kept confidential and tests, tape recordings and interview notes will be destroyed after the research is completed.

RISKS AND ACCIDENTS

Talking about your caregiving responsibilities and experiences may make you feel uncomfortable and sad. Should these feelings persist, I'll undertake to organise follow-up psychotherapy in the community where you live through the Provincial Government of the Western Cape's health pathway system as a matter of priority.

BENEFITS

The aim of the study is to reduce stress that is linked with your parenting experiences. We are not sure if treatment will help and there may or may not be direct benefits to you by participating in the study. A potential benefit of psychotherapy relates to lower levels of parenting stress. Skills that you gained to deal with stresses could also be used in other areas of your life. I am hopeful that our learning experience from the study could be shared so that people would become more aware of the need to provide support for mothers of adult children with intellectual disability and the challenges of managing their child's aggression.

CONFIDENTIALITY

Research material such as tape-recordings, written transcripts of interviews and therapy as well as the tests will be kept confidential. Your name will not be used in any publications of the study. Notes will not be placed in your child's hospital folder and neither will a hospital folder be opened for you.

COST OF THE STUDY

By participating in the study no costs are incurred to you and neither will you be expected to pay for any costs associated with the administration of tests or attendance of the psychotherapy part and interviews in the study.

PARTICIPATION

Your attention is drawn to the fact that participation in the study is completely voluntary. You have the right to decide not to take part in the study and you can withdraw at any time.

QUESTIONS

If you have any questions in regard to the study do not hesitate to contact the principal investigator or project coordinator at the University of Cape Town.

Prof Colleen Adnams	UCT	Tel	021 404-2173
Principal Investigator	Alexandra Hospital	Tel	021 503-5027
			021 503-5009

Questions regarding ethics should be directed to the University of Cape Town Research Ethics Committee:

Dr. Mark Blockman Head: UCT Ethics Committee Tel 021 406-6942.

CONSENT

As mentioned before, if your child is able to follow basic instructions the purpose of the study and need to attend appointments at OPD will be explained to him/her using simple, basic language. Following the process of explaining what the study is about and why it is necessary to attend OPD, we'll obtain consent from your child to visit OPD. If your child is not able to follow the instructions or understand the explanation provided, an opportunity will be given to indicate choice of attending recreational activities at Alexandra or not attending.

You hereby give permission to partake in the study. Your signature hereunder shows that you have decided to participate in this study and that you have read the above information of that is was read to you.

I have read the above information (or have had it read to me). I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. By signing this consent form, I give consent for myself to participate in the study with the understanding that attempts have been made to explain the purpose of attendance to my child as well.

Parent's Name

Parent's Signature

Date

Address _____ Telephone number _____

Witness **if one is present** (Type or print)

Signature of Witness

Date

If a researcher has explained the information:

I have explained all information and answered all questions related to this research project to the participant. I believe that he/she has understood the information in this consent form and has voluntarily decided to participate in the study.

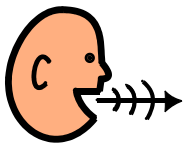
Name and signature of research team member

Date

Appendix C: Consent Form – Children of the Mothers who Participated in the Study

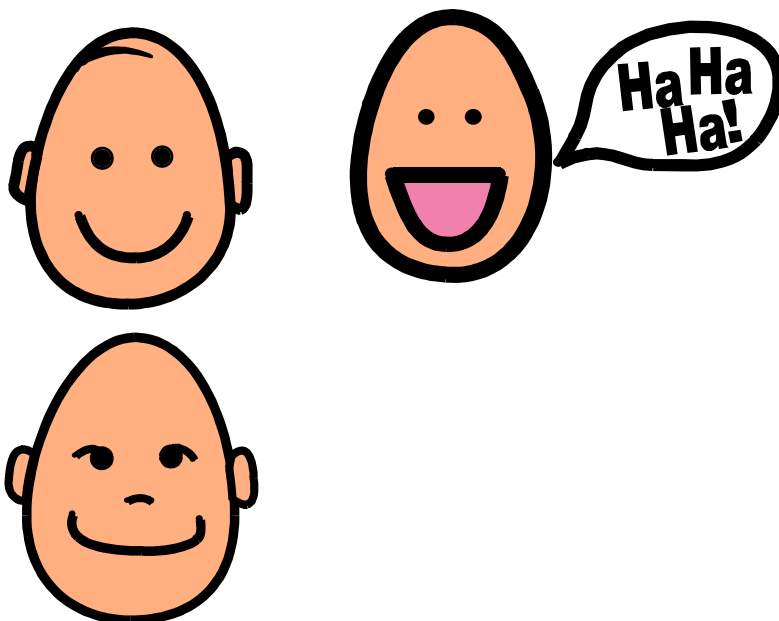
Psychologists and Feelings

Hello. My name is Ockert Coetzee. I work at Alexandra Hospital as a psychologist. Do you know what a psychologist is? A psychologist helps somebody by talking to them about their feelings.

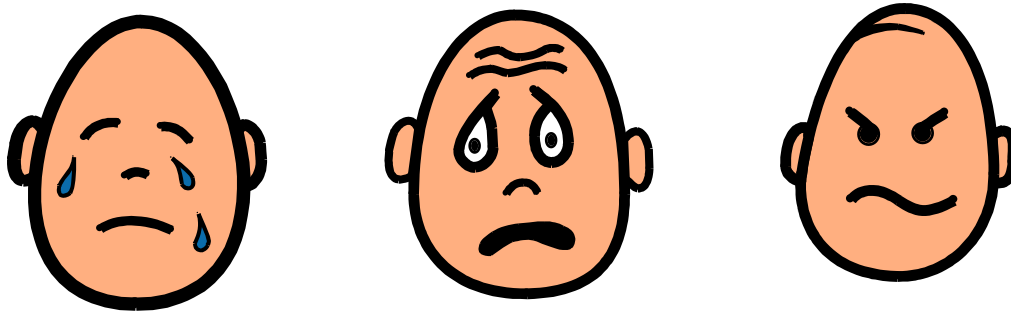


We get good feelings and bad feelings. Can you see below?

Good feelings



Bad feelings



Bad things sometimes happen to people. It makes people feel sad. People worry. People get angry. My work is to talk to people. Talking often makes people feel better. We can think about how to make the problem go away. Sometimes problems are too difficult to get rid of. We then talk how to make it easier to live with them.

For example, Ruth is an old lady who is ill. Her leg hurts a lot and she went to the doctor. The doctor told her that pills will not make the hurt go away. The pain is making her sad because she cannot walk to the shops anymore. She also cannot walk to her grandchildren to visit.

People like Ruth will often visit a psychologist. The psychologist will talk to Ruth about her feeling sad because of her leg. Together they will think of ways to make her happier again even if her leg remains sore. For example, the psychologist and Ruth might make a plan with her visits to her grandchildren. If they make plans so that her grandchildren visit her, Ruth may feel better.

We want to do a study



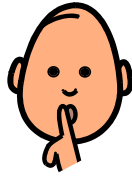
● The reason why you are at Alexandra today is because of a study. A study is when somebody wants to know more about something. Psychologists sometimes study how people feel about certain things. Look at this example:

A psychologist tries to find out why Ruth became sad. He will meet with her and talk to her. He may use a tape recorder. After he met with her, he may listen to the tapes. He might write things down. If he finds out more as to why Ruth is sad, he may write an article for a journal.

An article is like a very short book of only a few pages. I brought you examples of articles. You find articles in journals that are read by other psychologists. And other helpers. The reason why the psychologist wrote Ruth's story down is to help other people. How? The article is read by other psychologists who work with other people. Those people the other psychologists help may also feel sad. Maybe they don't see their grandchildren much anymore even though their legs don't hurt. See? The psychologists can then learn how to help those people by reading Ruth's story. They can see what helped Ruth to feel better... if she felt better by talking to the psychologist!

N

ames will not be used

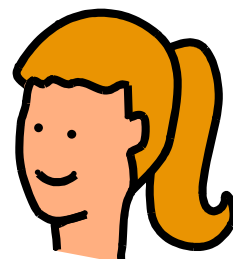
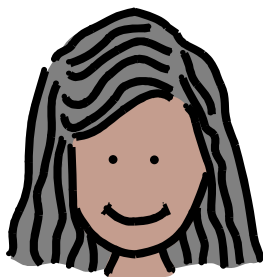


We shall not write something in an article and then use the person's name. For example, we shall not write "*John's mom felt sad that he was sick*". We will rather say something like "*One of the persons was sad that her son was sick*". If we write something down, we will destroy it after the study is finished. Tapes will also be made blank again. Psychologists sometimes write stuff that people say on paper. Why? So we don't forget what people said. Why not using names? Why destroy paper and tapes after the study is finished? It is about something called *confidentiality*. I want to learn what people's feelings are. Sometimes it is difficult to talk about the feelings. Sometimes you don't want strangers to know about your difficult feelings. That is why we do not take any chances – names will not be used!

W

hat the study is about

So, I'm a psychologist and I want to do a study. What do I want to study? I want to work with mothers.



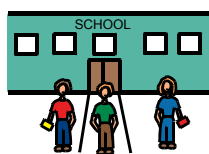
Any mother of a child? I want to work with mothers of children with a disability. I'm sure you have heard the word "*disability*" before? A disability is when the person needs more help to do certain things. For example, people who have a disability often find it difficult to do certain tasks. Tasks such as reading thick books or driving a car.



So, I want to do a study with mothers of children with disability. Remember what we said before – a psychologist helps people by talking about things. Things that make them sad or angry. Psychologists talk to people when they worry about things.

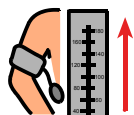
Because moms also worry

Mothers of children with disability also worry about things. An example is when the mother worries what will happen with their child if they are no longer there. Mothers may feel bad that their child has to stay home when other grown-up children have homes of their own. Sometimes mothers get angry that there are not enough



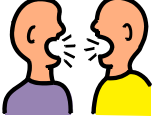
schools

for disabled persons. Or group homes.



Or doctors.

Or nurses and helpers. Mothers may feel sad or worried about their relationship with their child – maybe there was a

fight.  Maybe they fight a lot. Sometimes a mom feels sad

'cause that too few people help *her* to help her child. 

In the study I want to do, I'll meet with mothers to talk about these difficult feelings. We will talk about ways to make things better, to feel happier. Not to worry so much anymore. We use no pills, only talking.

Will the study make mothers feel better?



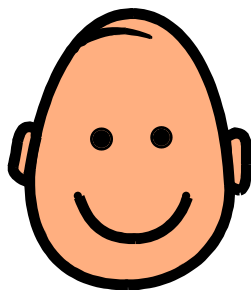
I really do not know if the talking will help. Sometimes it doesn't. We cannot say if it will help. We want to find out more about this problem. That is why we want to do the study.

Why I ask you if you are OK with all of this

Your mom will talk to me about her feelings and worries. That means that your mom may talk about you – how things are between you and your mother. Your mom may tell me more about things she

finds difficult – for example that there aren't enough schools and workshops. That she worries what will happen to you when she is not there anymore. Other things that are on her mind as a parent.

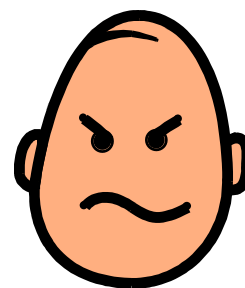
Your mom will be alone when she talks to me. I want to know how you feel about your mom talking to me. Because by talking to me she will also talk about you. I also want to know if you understood what we've discussed so far:



I am all right with my mom talking to Ockert about her experiences as a mom. I am all right that she may talk about me with Ockert. I understood what we talked about so far.

X

Child's signature



I do not want my mom to talk to Ockert about her experiences as a mom at all. I did not understand what we talked about.

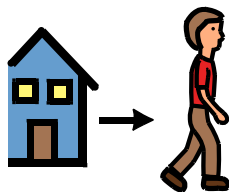
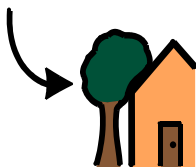
X


Witness's signature

Visiting Alexandra Hospital with your mom – your choice & decision

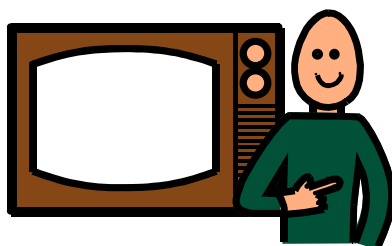
If you are all right to let your mom be part of the study, I want to tell you a bit more:

- I will meet with your mom every week at Alexandra for about 2 months or 8 weeks.



- It will be really nice if you can visit us when your mom comes in. However, if you do not want to come in, it is OK as well!
- I see your mother on her own. I asked one of the nurses  to keep you company when your mom is busy. We are planning fun activities. You might enjoy some of them:

- TV with a selection of DVDs.



- Puzzles



- Arts and crafts



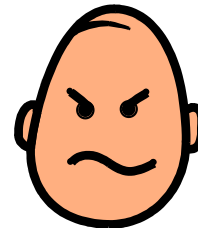
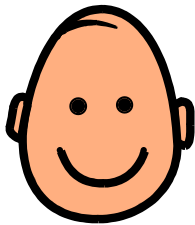
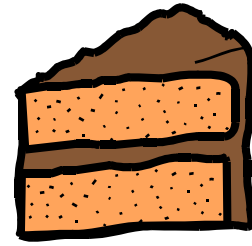
- Books



- Drawing



- There will be snacks and cold drinks.



I want to visit Alexandra with my mom.

I do not want to visit Alexandra

X

Child's signature

X

Witness's signature

Let's say that you come in with your mom when she visits Alexandra. Let's say after some time you do not want to come in anymore. That is ok as well – you can decide that you want to stop coming in. You will still be able to visit doctors at Alexandra. Or psychologists. Or nurses at Alexandra. We will ask no questions and won't be angry or upset with you. It is your right to decide coming in or not.

Appendix D: Ethics Approval from the Health Sciences Research Ethics Committee – University of Cape Town



UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Faculty of Health Sciences Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: sumayah.ariel@uct.ac.za

12 September 2011

HREC REF: 399/2011

Mr O Coetzee
c/o Prof C Adnams
Psychiatry & Mental Health
J-Block
GSH

Dear Mr Coetzee

PROJECT TITLE: PARENTING STRESS AND INADEQUATE COPING: AN EXPLORATION OF THE USE OF COGNITIVE-BEHAVIOUR THERAPY WITH MOTHERS WHOSE ADULT CHILDREN HAVE INTELLECTUAL DISABILITY AND AGGRESSIVE BEHAVIOUR.

Thank you for submitting your study to the HREC for review. We congratulate the principal investigator on this comprehensive and thorough submission.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

Approval is granted for one year till the 30 September 2012.

Please submit a progress form, using the standardised Annual Report Form (FHS016), if the study continues beyond the approval period. Please submit a Standard Closure form (FHS010) if the study is completed within the approval period.

Minor Corrections in the Informed Consent Form.

1. Under section headed Procedure, several words appear to be missing: "Fifth, a 1 hour(?) after you've finished psychotherapy....."
Sixth, with your permission the (?) are repeated 4 months after...."
2. Please refer to the Human Research Ethics Committee in the Faculty of Health Sciences.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

sAriel@uct.ac.za

Yours sincerely

Signed

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Appendix E: Number of Omissions and Additions of Sentences and Words as Assessed by a Third Party

In order to enhance rigour with regard to transferability, a transcript of a psychotherapy session in each case study was randomly selected and collated with the corresponding audio-recording by a third-party assessor:

Case Study	Number of omissions - sentences	Number of additions - sentences	Number of omissions - words	Number of additions - words	Was the meaning of the transcripts altered by the transcript errors?
Patricia	4	1	6	25	No
Linda	1	1	25	19	No
Jeanette	1	1	7	3	No
Hadil	1	1	15	10	No
Marlene	1	0	25	20	No
Sarah	0	0	3	1	No

Appendix F: Example of Data Reduction and Coding as Part of the Thematic Analysis- A Rough Draft of Codes that Were Generated From the Psychotherapy Sessions with Patricia

Excerpt	Coding
<p>Participant 1: Patricia</p> <p>Session 1</p> <p>Patricia: Like week was quite emotional for me, because it was like bringing up the past, you know, about, uh, through the years, uh, how did I cope? How did I cope?</p> <p>—</p> <p>Patricia: And especially what I found emotional was the fact that I did take to drink to cope.</p> <p>—</p> <p>Patricia: And which is uplifting today, I don't need a drink to cope.</p> <p>—</p> <p>Patricia: Because I believe that ... through God's help</p> <p>—</p> <p>Patricia: But I've got a programme that I tend to, therapy wise I would be drunk, continuously I would've been drunk.</p> <p>—</p> <p>Patricia: Hmm, because... I mean... to cope with it mentally for... because her birthday was actually Thursday but she thought it was Saturday cause we gave her a party on Saturday.</p> <p>OC: Yeah.</p> <p>Patricia: So it was the whole week: "My birthday on Saturday, say</p>	<ul style="list-style-type: none"> • Difficult to talk about past parental experiences. • A pile-up of life stressors and parental adversity. • Substance abuse as way of coping with parental stress. • Feelings of guilt w.r.t. substance abuse. • Belief that she is coping with stressors in a more functional manner. • Recovering from substance dependence. • Coping through positive reappraisal. • Psychotherapy as a difficult, emotionally painful process. • Significant life event during the week. • Child's repetitive behaviour as significant stressor.

birthday, say birthday”, and it’s like, in your face.

OC: Yeah.

Patricia: And I say “Birthday”. I say to =husband’s name=, “we must go to the shop now”; “Say party, say birthday, say party”. No matter what we say we can’t even have a conversation and it’s in your face, say this, say that...

Patricia: And it’s just getting worse, because like this morning... it’s like the stress, is she going to work today? Because I already planned that’s she going to work within a bugger up there on her way to come through here.

Patricia: So I still told her “we’re gonna fetch you lunch time”, and put less lunch in for her, and... I was like stressed – is she gonna go to work but what’s gonna happen this morning?

You know? Is going to tell us “I’m not going to work” and then I [inaudible segment]; and then by the time she calls me she was getting dressed, she won’t get dressed in her room anymore, because the guys on the TV’s gonna see her. She says she was getting dressed in the bathroom. And she called me... and I went... and she says... (long pause): “Leave me alone! What do I care?” And she didn’t realised she called me. And it is for me to...

OC: So sometimes it happens. Sometimes it happens, mm, let’s say that you were in a motor vehicle accident when you were 4 years old. Hmm, you thought you were going to... you were terribly injured! Uhm, and

- Worry and uncertainty about possible challenging behaviour: generalised anxiety – what if?
- Uncertainty and generalised anxiety linked with possible future behavioural problems of child.
- Child: Paranoid delusions and visual hallucinations.

<p>even today, uhm, when driving in a car, you think: “Oh, the world is a dangerous place!” and your thoughts are, uhm, “What if I make an accident now?”, that leads to an emotion of feeling sad of worried.</p> <p>—</p> <p>OC: . . . progress made, and if something very., hm, like stressful happened, we’ll put it on the agenda.,</p> <p>Patricia: [cross talk] Mm</p> <p>OC: ...you put stuff onto the agenda, I put stuff onto the agenda, you know, and we work through it.</p> <p>Patricia: [cross talk] Ja. Ok.</p> <p>OC: The agenda of each session would form smaller parts of goals setting. So, what are our therapeutic goals? We-we’ll be looking today at...</p> <p>—</p> <p>Patricia: [inaudible segment] I’ve come to terms with the seizures. If she’s having a fit tonight, ok, I’ve come to deal with that. Because I know we made a room safe for her.</p> <p>OC: Yeah.</p> <p>Patricia: And... ja. Just the behaviour... We can’t have a conversation, now if she was sitting in this room, I’ll be talking to you about... going home to make a cup of tea... And she’ll say, “Say coke, say coke.”</p> <p>OC: Mm.</p> <p>Patricia: So, it’s like stressful. No space, I’ve got no time to think.</p> <p>—</p>	<ul style="list-style-type: none"> • (Segment forms part of larger conversation to socialise Patricia to the CBT model): Past experiences have an impact on present thinking. To change thinking in the here and now even though schemas were formed in earlier years. • Socialising Patricia to the CBT model: Agenda setting, therapy goals, collaborative working relationship. • Physical health of child as constant stressor, but Patricia is coping with it and used to it. • Repetitive behaviour of child continues to be stressful:
---	---

OC: Okay, Patricia, so thank you so much for, ah, that was quite a long preamble to all of this. Now I want to ask you, thinking about Sue, thinking about Sue's problems: what... are the feelings that you experience? What are your worst ?fears?

Patricia: Anxiety. I'm full anxious. When Sue is around, I'm anxious all the time!

OC: Yeah, anxious.

Patricia: It used to be only for the seizures ...

OC
Mm-hm.

Patricia
I was anxious she's gonna have a fit...

OC: Ja?

Patricia: You know, are we going to hear, are we going to be ok but we've come to deal with it. We're talking about the here-and-now?

OC: Yeah.

Patricia: For now, it's just, having Sue around I'm stressed. I'm...

OC: Stressed?

Patricia: Ja... (plane in background) And it's only the behaviour problem...

OC: Yeah.

- Helplessness and feeling overwhelmed: I got no time to think (selective abstraction and polarised thinking)

- Maternal mental health: Anxious and stressed in child's presence due to possibility of behavioural outburst.
- Parental stress due to child's behavioural difficulties.
- Attribution: stress due to child's behaviour.
- Formative influence of poorly controlled epilepsy on apprehensive expectation that child will have seizures. Possible schemas denoting 'danger'?

Patricia: [inaudible segment] I've come to terms with the seizures. If she's having a fit tonight, ok, I've come to deal with that. Because I know we made a room safe for her .

Patricia: And... ja. Just the behaviour... We can't have a conversation, now if she was sitting in this room, I'll be talking to you about... going home to make a cup of tea... And she'll say, "Say coke, say coke."

Patricia: My-my mind is like... zonked. I can't think anymore. I mean, when she's around, I cannot cope!

Patricia: Because none of my children will be able to cope with her, because they can't cope with her today. They're hardly in her company.

Patricia: I'll curl up, I want to curl up under my duvet and just die. That is how I feel!

Patricia: It's a breakaway, and my youngest daughter, =husband's name= can handle Sue okay, although his stress levels are [inaudible segment], but my youngest daughter is going to come and stay there for a few days..

OC: Mm.

Patricia: ...and it's not going to be any different, Sue is not going to be any different..

- Coping with seizures through active problem-solving.
- Repetitive behaviour as stressor of parental stress.
- Repetitive behaviour as overwhelming parental experience.
- Intermediate assumption; core belief: ? I am an inadequate (as a parent); I am vulnerable.
- Cognitive distortion: discarding positive experiences when siblings cope effective with her daughter's behaviour.
- Maternal depressive symptoms, helplessness and hopelessness.
- Looking forward to life event – trip to another city as part of AA initiative.
- Cognitive distortion: Fortune telling
- Attribution of globality.
- Seeing AA trip as therapeutic – positive event.

OC: [cross talk] Mm

Patricia: ...but, she is going to stay there although she is sulking about it.
But ?they know? I need it; I need to go for my own therapy.

Patricia: Ja, so if it wasn't for this Wednesday coming...

OC: Mm.

Patricia: I'll be sitting here crying my eyes out, but it's lifting me up,
knowing I'm getting a break.

Patricia: Is =other daughter's name= okay? Because, I know there ?could
be? an outburst; there's going to be an outburst.

Patricia: I go once a week to my meeting, I feel guilty because I'm leaving
her. And ?it starts? feeling poor =husband's name=, he worked today
and...

OC: Mm.

Patricia: ...shame, he's got to, you know?

OC: Mm.

Patricia: Put up with whatever's going to happen.

OC: Mm. Mm.

Patricia: I do feel guilty.

- Maternal depressive symptomatology;
- Sense of helplessness.
- Positive experience of trip as uplifting.
- Cognitive distortion: fortune-telling; labelling
- Maternal guilt: leaving husband to look after daughter.

- Socialising client to CBT.

OC: Ok. Just to mention that many of the feelings you say are powerful thoughts.

Patricia: Mm, mm.

OC: "I feel guilty because =husband's name= has to work". That's a thought.

Patricia: Yeah. (Speaking slowly) And when I do walk out of the house, and I get into the car... Thank God I'm away from this.

Patricia: Which like, it's the only place, I don't go visit my sister for a few hours, or... without Sue, you know? And that's the only break I get without her. And people notice the difference in me...

Patricia: But it's a day to day process that, uh, I have to deal with, that I'm not coping with at all, but I'm doing it, because I have no other choice. I don't know...

OC: [cross talk] Mm.

Patricia: I don't have any other choice at this stage.

OC:
Yeah. Ja, ja.

Patricia: To do anything else; I don't know how to do anything else.

OC: Ok, so it's really a situation of, uhm, the impact of looking after Sue, not necessarily looking after her only but the responsibility that goes along with her behavioural profile that's really causing you considerable distress in other areas?

- Escape as coping strategy.
- Friends can vouch the difference when caregiving is not taking place, almost looking for justification – compensating for underlying guilt (tentative).
- Attributions that child is responsible for all her unhappiness.

- Cognitive distortion: polarised thinking – having no choice whatsoever.
- Helplessness.
- Resentful for having to look after child, can't do anything else.

<p>Patricia: [cross talk] Yes! Yes!</p> <p>OC: You can't do what you want to do, it's, it's difficult, and...</p> <p>Patricia: Ja.</p> <p>OC: You feel the impact if you're taken out of the situation...</p> <p>—</p> <p>OC: Feeling sad quite often?</p> <p>Patricia: Down.</p> <p>OC: Down?</p> <p>Patricia: Very down. Like I say, the only uplift-upliftment I got is when I'm ?with the AA?, otherwise it's you just like I say exist... You exist in that dome. You're not living. You're not happy, you know? You're not living...</p> <p>OC: Okay.</p> <p>Patricia: ...as such.</p> <p>OC: And it's stressful most of the week, every day?</p> <p>Patricia: Most days. Most days.</p> <p>OC: The biggest part of the day?</p> <p>Patricia: The biggest part of the day and w-weekend, ?just down? all weekend.</p> <p>OC: Ja! Okay. And you know, okay, when you feel like this, uhm, do you</p>	<ul style="list-style-type: none"> • Maternal depressive symptoms. • Helplessness and parenting. • Cognitive distortion: Generalisation of parental experiences to represent life in general.
---	--

<p>feel helpless that no matter what you do, nothing will work?</p> <p>Patricia: Nothing does work.</p> <p>OC: Ja.</p> <p>Patricia: With Sue’s behaviour problem. Nothing does work, and I’m not feeling good. Because, no matter what I do, no matter how I approach her, or bring up the subject of: Let’s do this or let’s do that to try make things better, nothing works.</p> <p>—</p> <p>Patricia: A long time and also... if I was a healthier person, if I didn’t have emphysema, if my hands wasn’t sore, I might feel a little bit better about doing things. But, everything I do... Even if... even if I didn’t get emphysema and my hands didn’t feel sore I would’ve been, for years I’ve been feeling down as far as Sue is concerned, but more so with the behaviour problem.</p> <p>—</p> <p>Patricia: It puts me off. It just makes, puts a damper on everything. Ja!</p> <p>—</p> <p>Patricia: And her music is playing in her room, and she’ll fall asleep and I’ll get up, and turn it down. Some days she says “Leave it alone! Don’t touch it!” It’s mine! Don’t touch it!” I can’t turn the volume down, so...</p> <p>—</p> <p>Patricia: I think I’ve said it a lot of times: “I wish I didn’t live anymore”. Uhm, I wish I could just sleep at night, wake up...</p> <p>OC: Mm.</p>	<ul style="list-style-type: none"> • Cognitive distortion: Polarised thinking. • Helplessness w.r.t. child’s behaviour. <ul style="list-style-type: none"> • Maternal physical health (emphysema) as having negative impact on coping; attribution that depression is caused by daughter, and more specifically her behaviour. <ul style="list-style-type: none"> • Cognitive distortion w.r.t. parenting: generalisation. <ul style="list-style-type: none"> • Idea that she can’t get away from constant stressors – even at night, music is playing. • Repetitive behaviour as stressor. <ul style="list-style-type: none"> • Hopelessness. • Guilt. • Suicidal ideation.
---	---

<p>Patricia: ...and then I feel guilty, immediately. I do feel guilty.</p> <p>—</p> <p>Patricia: But it's not... enough. It is not helping me cope with the situation but it's you see what I mean, it's giving me a bit of release.</p> <p>OC: Ja. It's social support.</p> <p>—</p> <p>Patricia: And I just kept, pushing myself forward, because I had to. I had to see the family, I had to see to my husband, I had to see to Sue.</p> <p>—</p> <p>Patricia: It's hectic. I can't. I just wish, you know, like I said I just wish somebody could ?grab? it, but if Sue's behaviour would be ok, we would be ok. We could cope better.</p> <p>—</p> <p>Patricia: Cause there's certain times of the year when her seizures is well under control. I call that time "Christmas time". I will bring her mattress into my room to put her ?under? my bed so I'm closer to help her.</p> <p>—</p> <p>Patricia: Hm. I was expecting, ja, we were actually expecting a scene from her if the DVD player didn't was, you know, wasn't there.</p>	<ul style="list-style-type: none"> • Coping strategy: Finding social support from AA meetings. • Cognitive distortion w.r.t. family life: imperatives. • Misattribution; intermediate assumption: Attributing family problems solely to daughter's behaviour. • Formative influence: Has to be on guard 24/7; constant vigilance due to daughter's epilepsy. Still prevalent thinking in here and now? • Helplessness w.r.t. parenting (protecting my child and making sure she is safe). • Event used to socialise Patricia into CBT. • Event – beliefs – feelings- behaviour. • Cognitive distortion: catastrophizing. • Physiological symptoms of anxiety and even panic.
---	---

OC: Mm.

Patricia: So that's why =husband's name= had that backup. But we didn't want to do it, and I was angry, because we had to give her a DVD player.

OC: Uhm.

Patricia: To keep the peace.

OC: Yeah.

Patricia: Because of people that are [inaudible segment].

OC: [cross talk] We'll get there just now, you'll see! So, thank you. Why "do I need to pick up this crap?" What else were you thinking? What was going through your mind? Automatic thoughts? (long pause). I felt..? Or I thought?

Patricia: I don't know, I felt down, I felt...

OC: Mm. What were you thinking? This is happening again?

Patricia: Yes, yes, yes. And it would... I thought then: It's happening again, but I was expecting it. (OC coughs in background). She was moaning already, and even from the day before, I was expecting a scene from Sue...

OC: Mm.

Patricia: ... to get her own way, with everything? for that matter. And I was, you know, I was expecting it.

OC: So this is happening again, it was expected. Why do I have to put up

- Feelings of sadness, anger, feeling terrified.

<p>with this crap? Your automatic thoughts. Uhm, what about your thoughts about solving the problem, i.e. aggression? Were you thinking about that or..?</p> <p>Patricia: That solving the problem was giving her a DVD player.</p> <p>OC: Yeah.</p> <p>Patricia: At that moment . . . Only to solve that problem, but not to solve (OC coughing) the bigger picture. Because there was more shit now with the DVD player.</p> <p>OC: [cross talk] Sorry, yeah. (Speaking louder) Okay, I'm gonna write that down! "I-am-going-to-cause-more-shit-giving-..."</p> <p>Patricia: The DVD player. Because...</p> <p>OC: [inaudible segment] Okay?</p> <p>Patricia: Unpleasantness, ja.</p> <p>OC: So you had an activating event, Saturday last week.</p> <p>Patricia: Yes, yes.</p> <p>OC: A couple of thoughts that we just identified. "Why do I need to put up with this crap? This is happening again as expected. And this one is also very significant: i'm going to cause more shit giving her the DVD player.</p> <p>Patricia: Mm.</p> <p>OC: So, the thoughts...</p>	
---	--

<p>Patricia: Ja.</p> <p>OC: ...lead to feelings. So, when you thought: “Why do I have to put up with th-this...”</p> <p>Patricia: I was anxious, feeling very anxious.</p> <p>OC: Anxious.</p> <p>Patricia: And I actually just wanted to ...burst into tears.</p> <p>OC: Sad?</p> <p>Patricia: Yeah, very sad.</p> <p>OC: And?</p> <p>Patricia: Disappointed.</p> <p>OC: Disappointed. (Long pause, birds chirping in background, people talking in distant background). Dis-a-poin-ted. And what’s the other one? Angry?</p> <p>Patricia: Ja, very angry. But I had to keep it in, you know?</p> <p>OC: So what did you do, eventually?</p> <p>Patricia: (Long pause). Oh well, we gave her the DVD player.</p> <p>OC: That’s it!</p> <p>Patricia: She got her own way.</p>	<p>Maternal anger.</p>
---	------------------------

OC: (writing down) Gave-her-DVD-player.

Patricia: [cross talk] She was over the moon about it, and I was very apprehensive. I was worried now, because with the DVD player in her room it brings all problems, because she doesn't want to work, she wants to stay at home and watch these guys singing. It's like a movie that she just watch. Yeah, she's got her own way.

OC: Can you see that because you were feeling these negative emotions you [inaudible segment], that's the behaviour. Now, by giving her the DVD player, you might actually have an impact on the next event that is similar.

Patricia: Yes.

OC: And that's how it works.

Patricia:
Yes, continuously, that is the circle, it's happening all the time.

OC: Hmm. Hm. So guess what: by changing anyone of these, you can change the others.

Patricia: By changing the fact that she mustn't get her own way? By being fearful. Because I'm fearful of Sue. I'm scared, I am terrified!

OC: Ja!

Patricia: And I don't like to be scared; I like to have peace and calm.

Patricia: We thought, if things [inaudible segment], if she's gonna, and Sue has.

OC: Okay. It's tough.

Patricia: And Sue knows it.

Patricia: And not giving her, her own way. I'm not going to work today. You can stand on your head! You can this, that and the other! I'll show you I'm not going to work. What do we do? We have to give in.

HOMEWORK ASSIGNMENT - DYSFUNCTIONAL THOUGHT RECORD.

Segment as example:

OC: Uhm, =client's name=, if you could just go and maybe, just identify 3 events. You don't need to write this exactly the minute after read them.

Patricia: Ja, okay. Ja, the time that I put it together then.

OC: Ja. Three events. What was going through your mind, i.e. automatic thoughts. (Long pause) And how did you feel?

SESSION 2

Patricia: You know that's nice, I was happy with that, but I was a little bit stressed, until I heard that =husband's name= had explained to her, soon after I left, that I'll be gone for a few days, and she was happy with that. I was stressing, because... I thought was she going to (sigh) be difficult with ?them? at home, you know?"

Daughter is responsible = attribution of responsibility; intentionality.

- Maternal anger.

- Apprehensive expectation about adverse caregiving event.
- Constant vigilance: Worried that child will act out if she is not there – constantly have to be on guard.

Patricia: And he's a good man, so I thank God for that, because I couldn't

- Husband as good, supportive person in her life.

been able to have this opportunity.

—

OC: Okay, visiting my sister, played DVD...

Patricia: Not working. The DVD player wasn't working.

OC: [cross talk] [inaudible segment]... Automatic thought: please let the player be working... Hmmm...

Patricia: It is so unpleasant today ?when visit? And this must happen, Sue is going to cause, she's already started to cause a scene, and it was, this getting bigger and bigger and I just wanted to go home [cross talk]...

OC: [cross talk] Home...

Patricia:
Cause I thought I want to go home now.

OC:
Yes.

Patricia:
The DVD player was not working, if it was working she'll go into the room and listen to the music there, and my feelings was disappointed, anxious and sad, now, because you know we come to visit these people and, once again.., the same story.

OC:
[cross talk] Yeah, yeah.

Patricia:

EVIDENT IN FOLLOWING CONVERSATION

- Homework exercise and example of visit to family with DVD player not working.
- Autism-related obsessionality.
- Acting out behaviour.
- Verbal aggression: child.
- Coping – escape behaviour.
- Maternal feelings of sadness, disappointment, anxiety, stress, anger, apprehension.

<p>No change.</p> <p>OC: Were you looking forward to the visit?</p> <p>Patricia: Yes.</p> <p>OC: Okay, okay. Uhm, listen...</p> <p>Patricia: [cross talk] It made it unpleasant...</p> <p>OC: Hm.</p> <p>Patricia: Because (people talking softly in background in the corridor)... I mean we come to visit. We come to have a chat.</p> <p>OC: Hm.</p> <p>Patricia: We [inaudible segment], and it ended up, of course, with my brother fixing it, fixed... and it started working.</p> <p>OC: Yeah.</p> <p>Patricia: And Sue was fine. She was bitching and moaning and ?all of that?</p>	
---	--

<p>Uh.</p> <p>OC: Upset, yes.</p> <p>Patricia: And, you know, the bad vibe...</p> <p>OC: Mm, mm, mm.</p> <p>Patricia: ...things like that, although they're used to it, they've been to our home often when this happens.</p> <p>OC: Hm.</p> <p>Patricia: They're used to it, but I don't expect Sue to carry on like this. Not accept (expect) is the wrong word. I don't like her carrying on like this in somebody else's home.</p> <p>—</p> <p>OC: remains the same and we'll keep on measuring it to see where we're going. Uhm, and then we also discussed last week what we wanted to get out of all of this. We thought about coping better with Sue behaviour, and to manage it, effectively...</p> <p>Patricia: Mm, yes.</p>	<ul style="list-style-type: none"> • Example of bridging from previous session.
--	--

OC:

...was certainly something that we need to cover. And we also spoken about this, uhm, feeling down and feeling low from time to time and basically, Sue, you're meeting the criteria of depression and, I mean...

Patricia: If it wasn't for my husband... this, this... ja. With his help, I manage, and I keep moving on, because he also needs me. My younger daughter, I don't just want to... curl up under the duvet. And also, what stops me from wanting to go to bed, I could easily just... climb into the blankets and sleep for the day. I fear for somebody's going to break into the house. I can't even go and lay on my bed in the afternoon. Cause I got that fear in me.

Patricia: It's very heavy on my mind, even in the room on the computer I get up every few, every now and again to go look if everything is okay outside, anybody walking in the road, ja, that type of fear.

OC: Ja, uhm, okay. So, Patricia, for today, what is it that you would like to p-put on the agenda and discuss from your side?

Patricia: Well, my main thing is to deal with thing with Sue. Instead of having to end wind up and anxious and you know, she starts on something...

Patricia: To get rid of those feelings and be like in charge... To be able to

- Worry.
- Hopeless.
- Maternal depression.
- Escape and avoidance as coping.
- Maternal mental health: worry about burglars (non-parenting event as significant stressor – apprehensive expectation and constant worrying).
- Feeling unsafe.

- Apprehensive expectation about possible break-in.
- Fear.
- Worry.
- Parental stress and constant vigilance even if daughter is not at home (contextually, she was at the workshop).

- Patricia wants to improve her management of child's behaviour as therapeutic goal and specifically on the agenda in this session.

OC: Mm

Patricia: But, uhm, and she kept on, what does addicted to love mean? And, uh, you know, little things like that made her very confused and irritable. "But they do love me, hey? But why do they say 'Addicted to love'?" which she kept on and she kept on until I couldn't (take) it anymore. Kept on repeating, repeating, so I called =husband's name= to come in, maybe he could get through to her.

—

Patricia: I... still need to put her away for her future in case something happens to either =husband's name= or myself so she's got a home, but... knowing that the behaviour is okay if...

—

OC: In a way the question is: if =daughter's name's= behaviour has such a devastating impact on you, what is the function of the devastating impact – why is it necessary to feel bad about something that is happening anyway?

Patricia:
All the time?

OC:
...all the time; anyway?

Patricia:
Why is it necessary to..? (Starts laughing)

OC:
Yes!

- Parental stress and worry about child's future placement as stressors.
- Gently disputing constant negative assertions – wanting to test the positive role of worry that could be part of GAD

<p>Patricia: 'cause it is the way I feel, I'm tired of it.</p> <p>OC: Yeah.</p> <p>Patricia: You know?</p> <p>OC: Ja.</p> <p>Patricia: I just feel I can't... (speaks softer) deal with this anymore.</p> <p>OC: Gatvol (Fed-up)?</p> <p>Patricia: Ja, gatvol! Tired of it!</p> <p>OC: Mm</p> <p>Patricia: Something must happen, we can't carry on with Sue behaviour anymore, because.., it (is) making our lives miserable, number one, =husband's name= and I c-can't have a conversation in front of Sue because, if I say, "cheese", she says... If I say to =husband's name= "Would you like a cheese sandwich?", she'll say, "Say peanut butter, say peanut butter." You know, it's like, putting a damper on everything. And I don't know if it's because... it's just me. No, it's not just me, we both feel the same way; anyone else in the company feels the same way. We can't talk another language.</p>	<p>Parental strain and parental stress because of child's behavioural difficulties</p> <p>Helplessness. Low sense of parental competence.</p> <ul style="list-style-type: none"> • Parental stress because of child's repetitive behaviour • Helplessness. • Cognitive distortion: Puts a damper on everything – magnifying and polarised thinking. • Idea that something's got to give – worry about future. • Worry about impact of stress on them. • Worrying about husband.
---	---

Yeah. It's all I want. And I don't want to cry. (Croaking voice). Ja, that's all I want.

OC:
Ja, ja. And thinking about this, day in and day out, it sounds like there's almost an invasive nature in which Sue will comment on things

Patricia:
[cross talk] [Inaudible segment] ...all the time

OC:
All the time. What does it mean to you when you want to have a decent conversation, Sue, and you can't, because of the interfering interjections from Sue t-that's interfering with that?

Patricia:
It means...

OC:
What's the meaning of that?

Patricia:
I don't know how to explain that the meaning of it.

OC:
Ummm

Patricia:
(Long pause) I would say it's just that, I don't want to say that I don't want to have company anymore, but it's best to me to be left alone.

OC:

- Downward arrow.
- Impact of child's behaviour on her social life.
- Loss of a healthy child.

Yeah.

Patricia:

But I don't want that.

OC:

Yeah.

Patricia:

I don't want to have visitors or not talk, when she's in the car and we're going somewhere we don't want to talk to each other, because it's unpleasant, so the meaning, I don't know, I don't know to explain to you the meaning.

OC:

It s-sounds like the meaning is that you almost want to stop the things...

Patricia:

Yes, yes

OC:

...you want to do because...

Patricia:

That's what it's all about; that's what it is.

OC:

Yeah, and...

Patricia:

I just don't want to carry on, because... and life can be so nice, and she used to be so pleasant.

OC:
Ja

Patricia:

I came home yesterday, I came in quietly at 04.00 in the morning. I didn't want her to wake up because then she would've turned the music up, because that's what she does first thing. So I came in quietly and I climbed in the bed and I thought "I just need to sleep". And then... a(n) hour and a half later I heard the music ?(go up, I thought)? "Oh, my God, don't tell me I'm still in the bus", because the music was playing loud on the bus as well. So (sighs), she came into the room, very happy to see me, "Hello Mommy, welcome home", and, loving. She is a loving child, gave me a big kiss and a hug and said "I've got something for you", and she went to her room and she ?(meant)? to fetch one of her little creams for me. But... But she c- can be a loving child but when she... when you're in a conversation, you got people around you, you're just talking to each other; just husband and wife or daughter and... little things, and... little things trigger her off. And you can't talk, have a conversation... (long pause) If I need to tell you something like my daughter sent me a message last night, I'll...?(her)? friend was in a car accident, a motor bike accident, serious, I couldn't say "Oh, shame, =husband's name=, did you hear what happened" and gone ?(to intensive), I know [inaudible segment]

Patricia: And we can't just . . . I can't switch off. Sometimes Peter can switch off and not hear. But I can't switch off to Sue; I hear her all the time!

OC: And the scene, it's almost like there's some kind of..?

Patricia:

[cross talk] She's gonna throw something or broke something.

- From mother's perspective: unreasonable demands and requests; unremitting. Nowhere to go.
- Ambivalent – also citing positive feelings towards child.

- Can't switch off – fuels apprehensive expectation: imperative thoughts and intermediate assumption of "In order to be safe, I must be on the lookout all the time.
- Constant vigilance as positive role of worry to achieve good outcomes – GAD>??

THIS SEGMENT:

<p>OC: Yeah, yeah, yeah. Sometimes people not only get automatic thoughts, but also automatic images. So, when you were seeing..?</p> <p>Patricia: I could picture my sister...</p> <p>OC: Yeah, yeah</p> <p>Patricia: ...with a little bit of patience, end up shouting at her.</p> <p>OC: Yeah.</p> <p>Patricia: And it would've caused bad vibes and...</p> <p>OC: [cross talk] You mentioned that, yeah, it's almost like a... you could almost picture like your sister shouting and..?</p> <p>Patricia: [cross talk] Because she hasn't got that much patience with Sue, and like I said, nobody is prepared to...</p> <p>OC: Ja.</p> <p>Patricia: Be more patient.</p>	<ul style="list-style-type: none"> • Exploring event, beliefs, feelings, behaviour = identifying automatic beliefs. • Automatic image in this case – anticipating a bad outcome. • Feelings of shame and embarrassment, but also anger. • Worrying about family conflict as result of child's behaviour. • Keeping the peace at all costs. <p>Cognitive distortion: Catastrophising</p>
---	--

OC:

Ja. Ja, ja, ja.

Patricia:

But they did try yesterday, like I said, they got the DVD going. And she was happy. And I thought: Why must a person have to go through all this? Just for peace.

—

Patricia: Yeah, so I didn't enjoy the visit, I was actually sorry we went there. We had coffee, chatted for about an hour and then we left, but I could've left earlier. I wasn't too happy to stay because I just felt, uh, you know?

OC: Yeah, because it felt...

Patricia: [Cross talk] Unpleasant. Yeah, and also because it is invading their home. Unpleasantness at their..., and they don't need it either. They might just said, agh no, don't worry about it, relax and it's okay.

—

Patricia: And there's like... there's (an) example we'll rather stay at home than put up with... the behaviour when we go out.

—

Patricia: You know, and then inviting us on Saturday because it is his birthday. I said: "Oh no, I don't think we'll be coming in on Saturday seeing what happened today". "Oh, we'll just [inaudible segment]". I said no. I can't do that to myself.

- Parental stress because of child's behaviour causing shame, embarrassment.
- Resentment?

- Coping through avoidance: Avoiding next family visit

—
Patricia: Ja, and the knot in my stomach (sighs), and: “Just please God, let this DVD player be working”, and then =husband’s name= was saying to her “Sue, if it doesn’t work it’s okay, we go home. We can play it at home...”

OC:
Mm-Mm. So, right now when talking about this, where would you rank your, your anxiety?

Patricia:
Oooh, hundred!

OC:
Hundred? Petrifying. Okay.

Patricia:
Yeah. He says “Don’t worry Sue, if it doesn’t work we’ll go watch it at home.” And she’s saying, “It is working, it is working”, and my sister’s saying. I don’t know what she was saying, she was just calm and [inaudible segment], but I could see... she was starting to work herself up.

—
Patricia:
[cross talk] Like I can...

OC:
Ja?

Patricia:
...easy, take her, hit her against the wall and say: “Enough!”

- Coping strategy to deal with stressful behaviour of child: avoiding family get-togethers with high possibility of acting out behaviour and aggression.

- Guided discovery to identify automatic beliefs – anxiety rating goes up to 100 during this interlude.

- Maternal anger and thoughts of hostility.

OC:

[inaudible segment]

Patricia: But I never do it, I can never do it, but I mean, I would never...

OC:

So where's the evidence coming from? So, just a couple of questions about those thoughts going through your mind – what is the worst that could've happened to you, and to Sue's name=, if Sue w-when you were thinking, "Please God, let this DVD player work"?

Patricia:

The worst thing that could've happened? She would've thrown something broken, or my sister would've... She would've thrown something broken and my sister... would've given her a smack or something. My sister's very short-tempered.

OC:

So when you were in the situation and you thought: If Sue acts out, uhm, if I...

Patricia:

It's not gonna go down nicely. Like we are gonna [inaudible segment]

OC:

[cross talk] And how much, at the time, how much of the responsibility were you taking..? For...

Patricia:

(speaking softer) I would say, I'll be taking all the responsibility...

OC:

THIS LONG SEGMENT: SOCRATIC DIALOGUE AND COGNITIVE RESTRUCTURING:

- Decatastrophising.

<p>All the responsibility!</p> <p>Patricia: Yes, because I wanted to just... didn't want it to happen, there was nothing I could do; there was nothing I could do...</p> <p>OC: [cross talk] So you took 100% of the responsibility?</p> <p>Patricia: I don't know.</p> <p>OC: Should anything bad happen?</p> <p>Patricia: Y-yes. Yes, yes.</p> <p>OC: Okay, and how did that make you feel, taking all the responsibility?</p> <p>Patricia: Not good.</p> <p>OC: Now let's go to your sister =sister's name= if you're okay with that Sue. =Sister's name= is..?</p> <p>Patricia: My sister is =sister's name= and her husband is =sister's husband's name=.</p> <p>OC:</p>	<p>Helplessness Cognitive distortion: polarised thinking</p>
---	--

<p>=Sister's husband's name=... Oh, I got it all wrong!</p> <p>Patricia: Her husband's =sister's husband's name=. She's...</p> <p>OC: [cross talk] Okay...</p> <p>Patricia: =Sister's name=...</p> <p>OC: =Sister's name= Oh, I'm sorry about that!</p> <p>Patricia: No problem.</p> <p>OC: =Sister's name=... She has a bit of a temper, you say?</p> <p>Patricia: She's got no patience... Very short patience.</p> <p>OC: Okay?</p> <p>Patricia: You know, she tries with Sue but I could see she wouldn't be able to cope with Sue for a day.</p> <p>OC: Mm. Let's say that she went along and she smacked her [inaudible segment].</p>	<p>Lack of social support: Family not understanding her daughter's difficulties. Idea of mom in the middle, mediating between family and her child.</p>
---	---

Patricia:
I would've been most upset, because you don't hit Sue, number 1.

OC:
Mm. Would you say that there was a possibility of =sister's name= lashing out at her?

Patricia:
Not yesterday, but I could s-see it, well, I would say it was possible, quite possible...

OC:
Yeah.

Patricia:
...if things have gotten out of hand.

OC:
Mm.

Patricia:
She might not have smacked her... Actually, it would've been possible if she had broken the TV or something.

OC:
Yeah.

Patricia:
She wouldn't take it lightly, she wouldn't put up with the crap I would've put up with.

OC:

<p>Yes.</p> <p>Patricia: But she always said that.</p> <p>OC: Okay, okay. So, I mean, if =sister's name= went on and smacked Sue, I mean, because we're talking about the worst that could happen...</p> <p>Patricia: [cross talk] Mm.</p> <p>OC: Not that it would've happened; would you have been responsible for it, fully?</p> <p>Patricia: (Long pause). No, I wouldn't have said it would be responsible for it, I would've felt...</p> <p>OC: Felt responsible.</p> <p>Patricia: Felt responsible. She's my child.</p> <p>OC: A hundred per cent responsible that =sister's name= lashed out at your...</p> <p>Patricia: I don't know, I don't know. I don't know how to answer that.</p> <p>OC:</p>	<p>Challenging existing belief system .</p>
--	---

Patricia:
It's not my fault!

Patricia:
It's not my fault. And I wouldn't have felt responsible, I hear what you're saying now, I wouldn't have felt responsible, I would've felt bad.

Patricia:
Upset.

Patricia:
All those feelings I would've felt but it wasn't my fault. I wouldn't do anything to... provoke it in any way...

Patricia:
And what would've come to my mind was: I should've checked if the DVD player was working. 'cause Sue did say to me "Mommy, could I play my DVD?" Play my DVD there. And the thought would've came [sic] into my mind. And you know, while I was there, it did come to mind, why didn't I just phone and ask if the DVD player was working?

Cognitive distortion: Imperative thinking.

<p>OC: Okay, so that is a possible way of coping... Sue, you know, problem-solving future incidents...</p> <p>Patricia: Ja.</p> <p>OC: [inaudible segment]</p> <p>Patricia: And then, I wouldn't have gone, I wouldn't have gone there, if the DVD, if they'd said the DVD player was not working, because... Sue wouldn't want to go.</p> <p>OC: Yeah. Ok, so two things here: If ?(ok)?, we'll get back to that just now. I think it will be a very good idea. Let's say that =sister's name= did make a scene, and it's-it's, because Sue...</p> <p>Patricia: It will more than likely happen.</p> <p>OC: And, and I mean, you were taking a 100% responsibility for what was happening.</p> <p>Patricia: Mm.</p> <p>OC: Just now, would you still take a 100% responsibility given that I think there</p>	<p>Problem-solving future episodes of potential aggression of child in the midst of social event.</p>
---	---

<p>should be a bit of responsibility from =sister's name= as well?</p> <p>Patricia: No, I wouldn't take... I won't be able to, no. And I'm not a 100% responsible for what happened; I would try to prevent it. I could do my outmost to prevent it.</p> <p>OC: Okay. Now, seeing that you have a child who is intellectually disabled., with one of the most complex profiles of epilepsy...</p> <p>Patricia: Mm.</p> <p>OC: ...and challenging behaviour; she has quite a bit of autism and an undiagnosed psychiatric disorder, meaning that...</p> <p>Patricia: [cross talk] Ja!</p> <p>OC: ...you know, her behavioural profile is extremely complex.</p> <p>Patricia: So therefore they try... and accommodate Sue. They try... and they get gatvol after a little while!</p> <p>OC: They're not trying hard enough?</p> <p>Patricia: Not hard enough.</p>	<p>Introducing complexities w.r.t. child's behavioural profile and maintaining conditions to aggressive behaviour.</p>
--	--

OC:
Okay. So given all of that now, the fact that she has a very complicated profile, the fact that they're most likely not trying hard enough...

Patricia:
They're not.

OC:
They're unreasonable. =Sister's name= was a bit unreasonable for having a temper, you know? [inaudible segment]

Patricia:
They do try! But then I can see, they also, they don't need this, you know? They also want to relax, you know, even if they with me... You know?

OC:
I want you to go now, you know, and think about the amount of anxiety you are now feeling about the situation?

Patricia:
[cross talk] My anxiety is very high.

OC:
Okay, but i-if you think about right now, Sue, even the fact that, you know, uhm, =Sister's name= should also take a bit of responsibility, given the fact that =Child's name has a very complicated profile, given the fact that lashing out... simply wouldn't make it right.

Patricia:
Uh-uh.

OC:

<p>About the situation that happened last week, if you take those in consideration, where would you rank you anxiety now?</p> <p>Patricia: At this moment? Because I'm here, and not there, it's not that bad! (laughs)</p> <p>OC: Okay, give me a number!</p> <p>Patricia: Seventy.</p> <p>OC: Okay. It came down now from 100% to 70%</p> <p>Patricia: Because it is not happening!</p> <p>OC: It's not happening?</p> <p>Patricia: It's not happening. When I'm in the moment, sjoe, it's high!</p> <p>OC: Yes.</p> <p>Patricia: I'm still anxious all the time.</p> <p>OC: Yes.</p>	<p>First pointer to the possibility that in situ experiences of child's behavioural outbursts and anticipation of same increase and maintain parental stress and anxiety.</p>
---	---

Patricia:
I'm a very anxious person all the time, but more so if Sue is around.

OC:
More so when =daughter's name= is around. Okay. What-what I'm trying to do, and we'll keep on doing it if it's okay with you..?

Patricia: You know? Like there is nothing I can do. Nothing I could do, nothing I could've done and ?(not go there)?

OC: Okay. So your automatic thought is quite negative, it is quite valid in this case. And now the question is – what use is it, to now feeling as anxious as you're feeling?

Patricia: Ja, no. You're quite right, what use is it, how do I not be anxious? You know?

OC: Hm.

Patricia: What is the use? You're quite right! Because it's still gonna happen. That's just come to my mind. Long ago, the thought has come to my mind, why did I stress so much? It was the same procedure, she did this; she did that; she broke this; she broke that, and I ended up in a state. I end up in a state. She's sorry afterwards, the deed is done.., and I end up in a state. So ja... (sighs). How do I not take all the blame?

OC: ...write me a little something about the way in which people, close to you, like your sister, =sister's name=, actually treats Sue, and the way it

- helplessness
- Validity of thoughts and feelings of anxiety about child's behaviour – now moving to usefulness of thoughts to set the scene for problem-solving.
- Core belief: I am to blame. (tentative, conceptually)
- Blaming herself for child's behaviour.
- Homework assignment – wanting to explore her beliefs about family support.

makes you feel.

Session 3

Patricia: She's like been Sue, repeating, repeating all the time. Not sleeping much. You know, that's been a bit of a worry. But there's been no outbursts. We've basically been doing everything to avoid an outburst.

Patricia: Because I wanted a break. When we got there they were quite surprised that we didn't bring Sue. I don't know what's been happening, but I've decided that if I need help I'll ask my daughter, my younger daughter. And then I did that. Once again, I said, "Listen, please we need a break, I need away time. And we've never done this!

Patricia: So we needed a break from =other daughter's name= and we needed a break from Sue and then we needed a break from =other daughter's child=.

Patricia: I said let us all just pray, please God help us here. Because sometimes she turns and says I'm not going anywhere.

Patricia: Okay, nothing happened, I'm still on my toes.

- Parental stress due to child's behavioural difficulties
- On question of how things are: immediately describing child's behaviour and possibly linking own psychological well-being with child's behaviour during the week.
- Significant life event: Attending family event without taking child with. Deviation from previous patterns of maternal behaviour (taking child with). Assertiveness?
- Inadequate family support.
- Family experienced as requiring "too much"; overwhelmed by expectations of other family members.
- Coping strategy: religion – positive reappraisal.
- Helplessness.
- Maternal mental health: Apprehensive expectation.
- Role of cognitive variables w.r.t. parental stress: anticipation of events linked with stress in the absence of significant behavioural difficulties.

<p>OC: Ja?</p> <p>Patricia: Because I'm waiting for her to start.</p> <p>OC: Yes.</p> <p>Patricia: I'm waiting...</p> <p>OC: [interjection] The anticipation of...</p> <p>Patricia: Yes, waiting in anticipation, but nothing happened. So I'm not that stressed, I'm not so... worn out.</p> <p>—</p> <p>Patricia: (long pause) (sighs) It's hard to say because, ja! Well, a lit... bit better I suppose.</p> <p>OC: (softly) Okay.</p> <p>Patricia: (long pause) I think it's also because when I come out of here I told =husband's name= what's happening.</p> <p>OC: Mm.</p> <p>Patricia: And [inaudible segment] that I'm talking about things. I'm talking about my feelings.</p> <p>OC: Mm.</p> <p>Patricia: And maybe that's also lifting me up a bit. I'm starting to come all right, you know?</p>	<ul style="list-style-type: none"> • Hope (that mood will improve through therapeutic process). • Lack of social (family) support NB: Disclosing to husband that she is using therapy to “discuss feelings” – is therapy validating that she has had adverse parental experiences that ?have not been (fully) acknowledged by husband (<i>tentative code – speculative</i>)
--	---

OC: Hmm, from that I was wondering if you could just think a bit about the impact of.., you know, stressful events like that and your relationship with family members and people close to you.

Patricia:
[interjection] Mm.

OC:
Uhm, to what extent that's contributing to your stress?

Patricia:
[inaudible segment] something does happen. Everything that Sue is kicking against the can and she's fighting and argue with us.

Patricia: If one of my other children interfere, either =husband's name= or I tells them to shut up and keep quiet and keep out of it. Because, the more people talk and say things when all of this is happening, the more... (long pause) ...out of control Sue gets.

Patricia: Like for example =other daughter's name= was staying... Okay, example. This is an example: =Husband's name='s car didn't start last night. So =other daughter's name= was by us, she slept by us Saturday because she looked after Sue. Sue was with us the whole day when [inaudible segment] the car didn't want to start. She slept there again last night. Straight away, we're stressing: =Husband's name= and I.

Patricia: Sue is gonna freak in the morning because the lounge isn't tidy. 'Cause =other daughter's name= is there. Now, straight away we start

- Child's behaviour's perceived impact on family strain (family relationships)
- External locus of parental control.

- Keeping the peace by parents placing themselves between child with ID and other children.
- Family tension, conflict and a lack of family support: Other children not understanding.
- Other children not supportive.
- Child's behaviour caused by other children's interaction with her.
- Maternal anger or ?frustration and resentment towards other children.
- Low arousal approach – “decluttering” when child goes into crisis.

- Inadequate family support from other children.
- Lack of understanding from other children.
- Child's behavioural difficulties: Daughter with ID's need for predictable environment.
- Maternal mental health: Apprehensive expectation and increased parental stress about possible behavioural difficulties.

stressing and worrying. And I say to =other daughter's name=: "=Other daughter's name=, we're leaving early tomorrow morning. I've got to be at Alexandra early. We don't need any... drama. When you open your eyes in the morning, this is how sick I am.

—
Patricia: Little things like that. No drama but I'm already pre-empting.

OC: Yes. Okay. Which is a way of dealing with the problem. . .

—
Patricia: And then she'll shout at =other daughter's name=. You know, and then like I'll end up telling =other daughter's name= "Leave her alone. Get out of the way." You know? "Don't get involved".

—
Patricia: But I could never ask her to look after Sue because she rubs the child rubs the wrong way. You know? You've got to know how to deal with Sue.

—
OC:
Yeah. Nothing, nothing urgent, or nothing that's really pressing that you would like to?

Patricia:
No, just to dealing with the child, you know? Just to deal with it, and

- Apprehensive expectation & increased parental stress.
- Worry – cognitive variables: what if.
- Uncertainty avoidance through confronting other daughter.
- Patricia in the middle: Keeping the peace
- Stimulus control: trying to prevent behavioural outburst by reducing unpredictability.
- Coping strategy: Problem-solving & accepting responsibility.
- Low arousal approach: knows child's triggers, tries to prevent outburst before it happens.

- Lack of support from other children to comply with management plan of child with ID's difficult-to-manage behaviour.

- (Context: part of guided discovery, topic on agenda: child's behaviour and its impact on family strain – situation - youngest daughter assisting with supervision of daughter with ID) Lack of family support
- Do not trust other children to manage her daughter's behaviour effectively.
- Worries that other children perpetuate child with ID's behavioural difficulties.

OC:
Mm.

Patricia:
ja. Otherwise, that's it.

OC:
Yes, Okay, Okay. If there's anything you think of during the week, uhm...

Patricia:
Ja.

OC:
...please? If you want to write it down, you know?

Patricia: If I just knew how and not to get so anxious...

OC: Yes!

Patricia: Like, I'm already visualising a scene this morning, you know?

OC: Mm!

Patricia: Cause I'm so used to it, and there was no drama this morning.

Patricia: When she came through the lounge which was slightly *deurmekaar* (in disarray). She turned around; she went back to her room and... (sighs). There was no drama, so if I could just learn how to... not... you know? Stress - looking for something that hasn't happened yet.

- Outerdirected .
- Process effort to enhance collaboration and initiative.
- External locus of control?

- Generalised anxiety: difficulty to control the worry.
- Automatic image: child's behaviour causing problems –apprehensive expectation.
- Cognitive distortion – Catastrophising – expecting that the worst will happen because the lounge is in disarray.

FAMILY TENSION AND PERCEIVED LACK OF FAMILY SUPPORT

- Unsupportive family.
- Family not understanding.
- Feeling hurt by family's lack of support and understanding.

Patricia:
Ja, I was more angry at Sue because, why must she perform like this again?
I can't have been really angry, it's not the right word. Angry with =sister's
name=. There must be another word... Disappointed, I don't know.
There's another word for my feelings towards =sister's name= because...

OC:
Mm.

Patricia:
She knows the situation, she is my closest sister. She knows the situation,
and I expected her to try harder. That's my expectation. (voices in
background in corridor).

OC:
Unsupported maybe?

Patricia:
Ah, very much so!

OC:
Okay.

Patricia:
And with my family, my sister. And my brother. Uhm, unsupportive.

OC:
And, and being let down? Is that too an issue?

Patricia: You know? When the crunch comes, they're not really that

- Maternal anger (from pitch and tone of voice and content).

- Lack of family support.

- Lack of family support

supportive. They'll rather back away and disappear. And because they don't know how to deal with Sue either, I suppose! You know?

OC: Yeah, yeah. You know what was actually so interesting and I think important last week, from our discussion last week? Uhm, on the one hand, Patricia, you were saying that *Sue is my child and I need to take full responsibility for her*. But then also on quite a number of occasions statements that you made that, you know, you're helpless here. You're...

Patricia: [cross talk] I realise that but I must act that out.

OC: Yeah.

Patricia: I do realise it, but I must remember it, and not get all into a panic.

OC: [cross talk] Yes.

Patricia: And let things happen, because I'm not in control of Sue. (long pause)

OC: Okay. So you're not in control?

Patricia: [cross talk] I realise that but I must learn how to deal with the situation.

Patricia: And =husband's name= also just say: "Get out of the room, I'll deal with that". You know, I just can't deal with it properly.

- Low sense of parental competence & external locus of control & low parental self-efficacy.

Coping strategy: taking responsibility.

OC: I want to be in control all the time, almost: I want to take responsibility for Sue's behaviour.

Patricia:
Yeah!

OC:
[cross talk] Ja, that's another thought!

Patricia:
No, hit the nail there!

OC:
How many visits have you paid to people? Let's look at the thought of being, you know, uhm, I should've, an imperative. How many people have you visited before whose DVD player wasn't working?

Patricia:
(long pause) None! (sighs). No, we don't go visiting much with Sue.

—

Patricia: Uhm, I've got another brother, =brother's name=. Older brother. But we don't visit often. Also, because, I took offense because he asked me, they asked me to come visit but why don't we get a babysitter for Sue?

—
Patricia: Ja, so I'm not visiting them. And I do realise I should visit. (sighs). I should get a babysitter for Sue. I expected, I didn't expect if from them, to hear that from them. And, you know, if I thought it was okay, I would've already... been there. Without Sue. But I'm still hurt I suppose. You know?

- Rejection of Sue by other family members/relatives.

- (Context not included in excerpt): Avoidance of uncertainty and anxiety –

<p>—</p> <p>Patricia: But now I think why the hell should I be visiting them without my daughter?</p> <p>—</p> <p>Patricia: Not one of them will say... Well, I know =other sister's name= will say to me. Agh, do you want to go shopping. I can't take Sue to go shopping. Because she just <i>goois</i> in the trolley. So =other sister's name= will say to me: "I'll come sit there for an hour or two". But I could never do that. Because if I leave them alone there will be a big scene. I know that because Sue, =other sister's name= can't handle Sue.</p> <p>—</p> <p>Patricia: I don't know. I was, didn't want to ask. Wi-with =other daughter's name=, I don't have a wonderful relationship. Because (background noise of somebody talking in corridor) she's... (long pause) wants to be a mother, you know?</p> <p>—</p> <p>Patricia[cross talk] (speaking much louder) Yes, if on occasions that we did go somewhere without her, on occasion, which was maybe once or twice a year. And to feel awkward, uncomfortable, because: <i>Shame, we left her behind, she's missing out.</i></p> <p>—</p> <p>Patricia: [cross talk] (speaking softly) I've been doing that all the time. (tremor in voice, speaking softer) Taking her with me forever, feeling guilty, because we're going out.</p> <p>OC: Yeah.</p>	<p>blaming herself that she did not phone sister to find out if DVD was working – cognitive distortion: I should have phoned my sister before we went visiting. Imperative thinking.</p> <ul style="list-style-type: none"> • I am to blame – core belief. BUT ALSO: • I am helpless (yet I am to blame) – conflicting? • Stigma? • Family not accepting child. • Anger towards brother. • Feeling hurt. • Cognitive distortions: Imperative thinking – one after the other. <ul style="list-style-type: none"> • Lack of family support. • Feeling guilty for not taking daughter with them to family event (past experiences) <ul style="list-style-type: none"> • Maternal guilt • Cognitive distortion: I have to take her with me when I go out, otherwise she will miss out.
---	---

<p>Patricia: And she's staying at home. (People talking in background in corridor outside) But staying at home, she is needing what she needs to do, or what she wants to do.</p> <p>OC: Mm.</p> <p>Patricia: So... (long pause). I've been feeling guilty for... so long... And, not doing what I should do.</p> <p>OC: Mm.</p> <p>Patricia: Living my life, and, uhm... Ja! (sighs heavily). And that's just for today. I've never taken her with. I mean I've always taken her with, never thinking of myself only. (Long pause)</p> <p>OC: And that's coming from somewhere! And, and I want us to talk, explore it a bit. Maybe not today,</p> <p>Patricia: [cross talk] Ja, it's just that I'm feeling high.</p> <p>_____ Patricia: Because I did it, on Saturday. I did leave her.</p> <p>OC: Well done.</p> <p>Patricia: Yes, coming from you now I'm looking forward I'm gonna do it</p>	<ul style="list-style-type: none"> • Could leave (adult) child at home and pursue own interests – appropriate boundaries.
---	--

again! Even if I do it once a month.

OC: It doesn't work like that. So what the guys actually go on about... you need your breaks. You need to plan your breaks without Sue. Not only because you need it, but also it's healthy for an adult child to spend time away from their parents.

Patricia: ...because you can't take her to the shop. I'm stressing – is she gonna be okay? So it was my thought: I am supposed to be there with Sue.

Patricia:
Is everything gonna be okay?

OC:
Mm.

Patricia:
That's my way of thinking.

OC:
Yes. And we are now exploring it, and we are trying to make sense: are these thoughts you have valid? Should we keep them or should we..?

Patricia:
[cross talk] (speaking much louder) No! We have to rid of it!

OC:
Yes, change it, if need be. [cross talk] [inaudible segment]

- Psychoeducation about need for respite and problems with sustained high levels of parental stress and burnout.
- Is taking child with her to social events part of avoidance of uncertainty – worrying and apprehensive expectation about possible behavioural outbursts at home while she is not with her child?
- Constant vigilance.

<p>Patricia: Yes. [cross talk] I am changing it already, if I'm not there, I'm not responsible.</p> <p>OC: Ja.</p> <p>OC: I don't think it's unreasonable to say that there should be somebody with Sue, you know? By the evidence you've given, you know, she tends to open the door for everyone.</p> <p>Patricia: Mm.</p> <p>OC: I mean, I know about your fears as well and the crime-crime situation in the city. So, I don't think that's unreasonable by any means. Uhm, what I want to know is the thought that I need to be with Sue. Is that valid or could we substitute you?</p> <p>Patricia: You could substitute me every time, yes!</p> <p>OC: [cross talk] Without feeling guilty, yeah.</p> <p>Patricia: Ja. Ja [cross talk] And that will help me move on.</p> <p>OC: Mm. Mm. And-and in the same way, you have thoughts about your-your family? Your close family and your broader family [sic].</p>	<ul style="list-style-type: none"> • Evidence for the belief that she should take her child with her wherever she goes. • Realisation that feelings of guilt are not based on empirical evidence, but difficulty in letting go.
---	---

<p>—</p> <p>Patricia: Honestly! That will take just about the whole picture.</p> <p>OC: Yeah.</p> <p>Patricia: Behaviour! I can't function, I can't socialise when Sue's behaviour is not...</p> <p>OC: Mm.</p> <p>Patricia: On par.</p> <p>OC: Mm.</p> <p>Patricia: So, basically the whole one! Ja, giving that little bit of space, ja. Ja.</p> <p>OC: Okay. Thanks for that. It's all her behaviour. Ja, there's it again. It's all her behaviour. Not quite all. It's a bit, a-and, you know, I know it sounds ridiculous but-but eventually, uhm, you know... You don't need to take all the responsibility.</p> <p>—</p> <p>OC: Think a bit about it. And also, I'm picking up on stuff that we haven't really touched [inaudible segment]. But, how much support is =husband's name= really giving to you? What does he expect you to do when it comes</p>	<ul style="list-style-type: none"> • Part of homework assignment – to think about and write down what her feelings and thoughts are about family support w.r.t. caregiving. • Ambiguity towards husband and disagreement about the management of Sue's behaviour.
--	---

to Sue?

Patricia: Just to give, ja-ja – just to give in all the time.

Session 4

Patricia: Uhm (sighs again), otherwi-, other than that it's been uneventful. You know, peaceful besides Sue keeping us on our toes.

OC: Yes.

Patricia: No drama, no bad news... No good news. Uh, ja.

OC: Ja. Okay. (long pause). Okay, so Sue's behaviour for the week: How has that been?

Patricia: Her behaviour... (sighs) is maybe, there's been no outburst.

OC: Uh-huh.

Patricia: Uhm (sighs), simply because we didn't give her, her own way.

—

Patricia: Most times she'll say: "What are you doing in my room? Get out of my room! Don't touch my stuff."

OC: Ja, ja.

Patricia: ?At other times? just "Leave my DVD player alone." And that is

- Feeling stressed and depressed despite absence of behavioural problems.

- Catastrophising
- Apprehensive expectation
- Life event: Child playing music throughout the night.
- Helplessness w.r.t. to be assertive towards child due to anticipated behavioural outburst.

the problem... Disturb sleep because, she... like none of us, my husband and I can't just go to her and say: "You're gonna turn it down now."

OC: Mm.

Patricia: 'cause, it will be a whole big outburst, and she will break something. Something is gonna be big, a whole big thing.

—

Patricia: So what's happening, and it's causing great vibes, is... I want to stand up to Sue and say: "No!"

—

We cannot, we can't carry on like this, I need my sleep. My husband's telling me, "Patricia, stop. Say nothing." Just trying to keep the peace. He's the peace-maker."

—

Patricia: And, this is what's causing bad vibes between me and him. Or him and I. Because... (very softly) don't know. (sighs). For example, last night...

OC: Mm.

One: What happened last night? She called me. I said "I'm coming Sue". She expected me to be there immediately.

OC: Hm.

One: And then she raised her voice: "I'm calling you, come!" She gets very abrupt.

- Disagreement with husband about need to become more assertive in managing Sue's behaviour.
- Cognitive dissonance w.r.t. wish to be assertive vs. fear of behavioural outbursts due to assertiveness.
- Becoming more assertive but worried about consequences.
- Keeping the peace through letting child "getting her way".
- Cognitive dissonance: P wants to become more assertive vs husband's wish to keep the peace.
- Intermediate assumption: Can keep the peace by giving Sue her way.
- Problems with family support: disagreeing with husband w.r.t. managing Sue's behaviour.
- Child's behavioural difficulties: demanding behaviour.
- Constant vigilance = husband.

OC: Mm. Mm, mm.

One: "Come here now!"

OC: Mm.

Patricia: With that, =husband's name= go running!

—

Patricia: I can't tell you what went through my mind!

OC:
Mm.

Patricia:
But anything to prevent a scene. Sue must learn that "I'm coming now, I'm coming now" is a matter of just taking my hands out of the dishes. I'm drying it but she wants me to be there already.

OC:
Ja.

Patricia:
Like I said before, I don't know if she already called me, then I never heard. Maybe somewhere in her head she's called me but I never heard her.

OC:
Mm.

Patricia:
But when she does call me she wants me to be there immediately! And as

- Using CBT language.
- Wish to change behavioural management strategies imply collision course with husband.
- Parental stress due to child's behavioural difficulties.
- Current management considered as unsustainable.
- Maternal physical health's impact on caregiving: Emphysema and running.

you know I've got emphysema and by the time I run to wherever she's calling, I'm already: "Yes, Sue, what's wrong? What do you want?" And she looks at me and Sue can pick up a vibe immediately. And then again last night: By the time I got to her =husband's name= was already coming down the passage to "Yes Sue, what's happening?" And he's laughing and he's making... uhm, things, making light of things.

OC:
Hm.

Patricia:
You know?

OC:
Minimising it?

Patricia:
Yes! To-keep-Sue- happy.

OC:
Yes.

Patricia:
To keep the peace. Whereas I... if I had my way, I will say: "What the hell do you want? Can't you wait?" You know? And I can't do that! Besides, if I did do it she'll freak. And besides =husband's name= is keeping me back all the time.

—

OC:
Right. Thank you for that Sue. Uhm, so-so we did last week talk about thinking, almost as a homework assignment or self-help assignment, what

- Keeping the peace by giving Sue "her way" = husband.
- Family support: "keeping me back all the time."
- Cognitive distortion: catastrophising.
- Maternal anger about child's behaviour.

- Homework assignment.

your expectations of-of family members... what the family is expecting from you?

Patricia:
Hmm.

OC:
So, did you, did you have a bit of time to think about it?

Patricia:
To be very honest with you, I did think. But I'm not getting much of it! I did think: where does the family help, where does the family fit in?

OC:
(softly) Yeah.

Patricia:
But they don't really. If I ask them to do something. If I ask them... they will do it. Not whole-heartedly... (long pause) Uhm, =husband's name= just does everything for Sue to keep the peace; he'll bend over backwards! Just to save a scene; to save some drama. Sometimes I feel...

OC:
Hm?

Patricia:
Not always, but I do have this feelings at times: if she's gonna break something, let her break it! Because we can't keep on... we're suffering to keep her happy!

OC:
Ja.

- Problems with family support: disagreement with husband.
- Wish to be more assertive but husband is opposing assertiveness.

- Ambiguous feelings regarding husband's support in the management of Sue's behaviour.

- Cognitive dissonance about keeping the peace through non-assertiveness and giving her “her way”.

<p>Patricia: And sometimes I do feel: if she's gonna break the window, let her break it, let her hit it broken! Because we can't keep on trying to keep the peace; everyone else is suffering for it. We can't have a conversation in the house. We can't do things, we can't go somewhere.</p> <p>OC: Mm.</p> <p>Patricia: But we can't do what we want to do, because we got to... (sighs) Again, we've got to walk on eggshells in front of Sue.</p> <p>OC: Mm. Hm-hm.</p> <p>Patricia: And this what's I find very difficult is... (long silence) =Husband's name= and I can't work together with her. The way, maybe it's just my thinking. The way I want it. But be more firm, and accept the consequences. He doesn't want a big scene. I don't want; I don't like drama but sometimes I feel: Let her scream and shout... she... I can't just be there. If I'm on the toilet she wants me to be there if she calls me. So just little things where I'm at, at the moment. Because of what happened last night... I'm angry at =husband's name= and Sue, because...</p> <p>OC: Okay.</p> <p>Patricia: Because of circumstances. The way she expects a person to be there and =husband's name= come running because I'm not there fast enough...</p>	<ul style="list-style-type: none"> • Keeping the peace through walking on eggshells. • Dissonance about keeping the peace. • Expressed need to become more assertive. • Anger towards husband.
---	--

—
Patricia: [cross talk] Didn't worry un-until I started speaking about it. It didn't worry me before.

—
Patricia: And I said, I said to =sister's name= on... When was she there? S-Sunday. We invited them around for a snoek braai. And I said to =sister's name=: "You know," – she asked me how it's going with this business. So I said it was going good and that I find it very emotional when it comes to my family. She says: "What do you mean?" So, I said to her: "Agh, I'll explain to you one day." No it didn't, wasn't... in that space to explain to her all about... (sighs) What it's all about. I did-did tell her a little bit that the... about the emotional side of looking after Sue, and having family I would like... I would like them to step in every now and again.

OC: Mm.

Patricia: So, she says it's difficult but she's now working. But I said: "No, I'm not asking you to look after Sue". I did explain that. And then =sister's partner=, her fiancé walked into the kitchen. And he says: "Mm, what you're gonna do now? The DVD player is not working."

OC: That's a bit odd now, isn't it?

Patricia: So, I fel... was hurt by that.

OC: Ja?

Patricia: He says, "Have you got any lemon?" I says: "Yes, there's lemon on the vegetable rack. You must pour in yourself a drink. =Husband's name= and I don't drink at all."

- Process of therapy: thinking about family support – did not consider it before therapy.
- Lack of family support – sisters and extended family.
- Sister's husband "soek skoor" – hurting Patricia.

OC: Mm.

Patricia: So he opens the fridge... (Long pause) So that's when he said: "What are you gonna do now that the DVD player is not working in her room?" I said: "No, =sister's partner's name=, it's fine." "We're not gonna come and cause a scene there, are we?" That's all I said.

—

Patricia:
Because I was angry, that's why I...

OC:
Yeah!

Patricia:
...said: "What are you doing; are you taking stock?" I mean, instead of just being open about it, more... You know, "=Sister's partner's name, it was something nasty you said."

OC:
Mm.

Patricia:
I should've asked him: "Don't you want us there? Is Sue disturbing you so much?"

—

Patricia:ross talk]. No. You know what happened on Saturday? Pardon, we went to =husband's name='s brother, we had to go take something there. And then, they stay in the same area. =Sister's name= and

- Anger towards family members (brother-in-law) - criticising and even ridiculing Sue.

- Standing up for her child.

- Getting more assertive towards husband.

=husband's name='s brother stay in the same area. S-so, Sue asked, Sue has her DVDs with her wherever she goes. She takes it with. Sue was watching it a bit at =husband's name='s brother's place. Then she said: "Come, are we going to Aunty =sister's name= now?" Because she wanted =sister's name= to come braai with we. So I said: "=Sister's name= is coming with us tomorrow, so we're not going there now." So =husband's name= said: "Ag, let's just pop in." So I said I'm not interested today; we're going to see them tomorrow. So =husband's name= ?said?, "We're just going for 5 minutes". So I said that in that *geval* I'm not interested, I'll just wait in the car.

—
Patricia: Because I knew Sue is going in with the DVD, and it's gonna be a problem.

OC: [cross talk] It's gonna be a problem!

—
OC: ...because you are already managing it.

Patricia: No, I don't think so. Not managing it. It's not, it's unmanageable!

OC: [cross talk] Mm! It is unmanageable in many ways! But the plan to t-try and come to...

Patricia: ...manage it better, be more relaxed and...

OC:
Be more relaxed and to cope with it.

- Coping through distancing and avoidance..

- Cognitive distortion: Anticipating worst based on previous experiences – to an extent selective abstraction and arbitrary interference (also previous times when Sue did not display problem behaviour and no indication of agitation).

- Cognitive distortion – discounting the positive.
- Cognitive distortion – generalisation.

- Referring to epilepsy and psychosis .

- Agenda: Discuss family support to enhance coping with child's behavioural difficulties.

Patricia: The coping. The coping is it.

OC: And-and, in order to place you in a position to cope, I thought it was important to look a bit at your levels of support. And, I think we did explore that a bit.

—

With =sister's partner's name's=: "Oh, what you're gonna do now? The DVD's not playing?"

OC:
Yeah.

Patricia:
Bastard!

OC:
Anger?

Patricia:
I was angry. That was my thought.

OC:
[cross talk] [inaudible segment]

Patricia:
And, you know..?

OC:
Okay! Like a let-down. A "let-down" and angry

—

- Process: identifying automatic beliefs.
- Guided discovery
- Situation: brother-in-law asking her about DVD player.
- Thoughts: Bastard! Oh, you're gonna do that now! Can't he just leave me alone.
- Feelings: anger and sadness.
- Behaviour: confronting him to ask if they were not welcome.

(exploration afterwards – p.41): Cognitive beliefs – we won't visit them anymore because we will feel too embarrassed. We are being let down. Feelings of disappointment and anger.

- Automatic thought: (same situation) – family hostile towards her due to child's behavioural difficulties – family support issue.

Patricia: Ja, disappointed, let-down. I thought – why are you being nasty to me? It felt like he was nasty to me.

—

Patricia: Like I said: Mess with me, but don't mess with Sue.

—

Patricia: Like he's got no time. Or, maybe that's the way I saw it, he hasn't got the time. He doesn't want to be bothered about...

—

OC:
But in a previous session you also mentioned that it's difficult for you to speak up.

Patricia:
Hm.

OC:
And to be a people's pleaser, I think.

Patricia:
Rather say nothing to keep the peace.

OC:
Ja. To keep the peace. And that sounds as if...

Patricia:
[cross talk] It's also...

- Protective towards daughter.
- Lack of family support and indifference towards Sue (extended family).
- Perceptions of self as people's pleaser.
- Non-assertiveness and difficulty speaking up against family.

OC:
...it resonates with =husband's name=s way of dealing with Sue's
behaviour.

Patricia:
Yes.

—

Patricia: I don't know if that would bother him, really. Whether that
would bother him or not.

OC:
[inaudible segment], I must confess. So, if you were to give him one
sentence back: something like, "I do not like it when you talk about Sue in
that way." Would that help?

Patricia:
Ja, it would.

OC:
Okay.

Patricia:
Ja, it would.

OC:
So what we also need to focus on is to-to, what is called assertion training.

—

Patricia:

Behavioural rehearsal and assertion training.

(context here is talking about ways of becoming more assertive towards family –

OC:

- Homework for next session: DTR - 3 or 4 events.

So, how can we change the thought? Because the thoughts lead to feelings and different behaviours?

—

OC: But for the next session (coughs). Sorry. It might be useful to try and identify 3 or 4 events. And you don't need to do it when it's happening, you can always do it a bit later.

—

Patricia: "Just tell Mommy she's not the boss, you're the boss."

OC
Hm.

Patricia: In other words... No, she likes... I can't explain it. She's... When she's, then =husband's name will say: "Yes, yes =daughter's name=, you're quite right, you're quite right!" And then I get these angry thoughts: why is she playing the one up against the other?

—

Patricia:
(Airplane passing over building causing background noise). But she manipulates to get her own way. She might be retarded, but whatever she is, she knows how to play the one up against the other . . . when she can't get her own way: "I'm not going to work now."

OC:
Mm.

Patricia:

- Child splitting husband and Patricia.
- Husband does what child says – maternal anger the result.

- Attribution of intentionality.

Or: "I won't go to work. You can stand on your head I won't go to work!"

OC:
Mm.

Patricia:
This is the words that comes out of her mouth.

OC:
We're not worried about the disability part in that context. I mean, if you work in the field, people with disability, uhm, also have emotions, they also manipulate; they also get angry.

Patricia:
[cross talk] Mm. Mm.

OC:
Wha-what is important to me about this situation is that, if anyone – whether you have disability or not – uhm, talks to you in that manner: "Why is your face like that?" Uhm, she knows very well that you are ill with emphysema.

Patricia:
[cross talk] Hm, hm.

OC:
That will, you know that will have...

Patricia:
It does [inaudible segment], you know, it upsets me!

OC:
That's not right.

- Parent-child interaction: Sue ridiculing Patricia – hurt by that.

Patricia:
It's not right because where is she coming from?

OC:
[cross talk] Mm, mm.

Patricia:
Why is she saying this? And then she'll look at me, and she'll want to laugh. You know?

—

Patricia:
Oh sure, I mean I want to give her a smack.

OC:
Yeah.

Patricia:
I want to. That's what's going through my mind. If only I could just give her a smack, but I can't do it.

—

Patricia: Start it again. And I don't like it, so she'll call and I'll tell her: "Sue, I am busy. You are sitting there, doing nothing." She is sitting there in the lounge and she wants me to change the thing in the d-, in the bedroom. (sighs) And it's loud. And it's got to be loud, so she can hear it while she's in the lounge. And I'll say: "Sue, you are sitting here doing nothing, you can do that." (silence) "Daddy!"

- Maternal anger towards child.
- Coping through self-controlling.

- Parental stress due to child's demanding behaviour.

—

Patricia:
(Long silence) And I know what his answer might be: “Ja, but you know what’s gonna happen if we don’t give her, her own way?” We are, I agree. It ?does matter? to give her, her way with everything. Little things we cannot give her, her own way. Like I said, (sighs heavily) she can change her own DVD when I’m busy. Or, you know, I might be in the shower and she’ll shout: “Mommy, stop the DVD please I don’t like it.” Mm, mm. And yes, =husband’s name= will come running in and [inaudible segment]. Yes, little things like that he’ll say: “But you know what will happen if she doesn’t.” My point is, she’s not gonna make such a big scene if she knows I am in the shower.

OC:
Ja.

Patricia:
And she’ll have to go do it. Why does he come running? Little things we can work on together. That is my point.

OC:
Yeah.

Patricia:
I could try. I wouldn’t like to have him in on that without me sitting with him once again. I could tell him what the session was about. And it came up...

OC:
Hm. Mm.

Patricia:

- Problem-solving ways of approaching husband to discuss her unhappiness about his management of Sue’s behaviour.
- Husband also fearful that Sue will become aggressive.

...in the session, and it is worrying me. I mean, if it wasn't worrying me I wouldn't have mentioned it. And to ask him: "Can't we work on that; otherwise you'll have to come in to get some guidance on it?"

OC:
Mm.

Patricia:
I can do that.

OC:
Mm.

Patricia:
Because if he's... ja.

OC:
Let's first think a bit. I hear what you're saying. And he might actually construe it as...

Patricia:
Hm!

OC:
...uhm, "Yeah, but we're already doing this."

Patricia:
Ja!

OC:
So?

Patricia:

If not, let's. If I have to then. If we have to later on, fine, but I'll try. I'll sit with him again, tonight, and explain to him... (silence) ...what's come up today. And what I spoken about, and with this little issue of him going running all the time. There's certain times when he can come forward...

Session 5

Patricia:
Just Sue's behaviour.

OC:
Yeah. Tell me more.

Patricia:
From the word go. It's Saturday morning...

OC:
Uh-huh.

Patricia:
Lashing out all the time, very unhappy. She's been very, very unhappy child.

Patricia: Whatever you say to her, you can't reason with her. Example: Saturday morning. "I want to go to the Spur today." And argue the point that she's going to the Spur. And we don't take her to the Spur today, because we're gonna take her the whole week.

- Minimising feelings about husband's management of Sue's behaviour.
- Process: Bridging from previous session.
- Parental stress and depressive symptoms directly linked to deteriorated behaviour – child.
- Demanding behaviour.

Patricia: So, I made her a cup of tea. I said: "Sue, the tea is on the dining room table." And she passed me, and she swung around: "What'd you say? What did you say?" And she just went ballistic. I said to her: "The tea is on the dining room table." And to me, she heard something else. Because she was angry with me! "Don't say that!" You know, that type of thing? So I explain to her again, but I'm shaking out because I'm scared, because she's gonna lash out at me again! Explain to her again: "Your tea is on the dining room table." (sighs) And then throughout the day she was very difficult. For everything we said and did wasn't good enough. She argued every point. That was Saturday. Sunday, the same story. I was stressed the whole weekend with Sue!

—

Patricia: You know, just praying: Please God, let this end quickly. Let Sue calm down.

—

Patricia:
Uhm, ja. That was Sunday. Monday, =husband's name= need to work. I was alone with Sue and she was making Provita biscuits. I made her some [inaudible segment] biscuits. I said: "Don't you feel like a sandwich? Have an avocado sandwich." She said: "Ja, sure." She was standing there next to me in the kitchen. I said: "Don't you want to go sit at the dining room table, you just now stand here?" And, she finished her avocado pear sandwich and I said: "Would you like..?" She said: "Could I have some Provita biscuits with cheese?" I said: "Yes, sure." And then I started buttering it. And then she took the knife away from me and said: "Mommy, I'll do it." So, agh... Okay fine, everything was okay.

OC:
Mm.

- Child's behaviour: unpredictable.
- Parental stress, fearful, scared.
- Anticipating severe behavioural outbursts.
- Helpless.

- (Butter scraping episode)
- Passive – coping through religion.
- Helplessness.

- Explosive behavioural difficulties.
- Child irritable.
- Maternal helplessness valid.
- Focus should more be on management of behaviour & parental skills

Patricia:
And I turned around, came up with the dishes. And I said: "Sue, take some butter off the biscuits." 'Cause I didn't say it, but I was thinking: There's more butter than biscuits! I said, and I said it nicely because...

OC:
Mm.

Patricia:
Uhm, you know, you have to be careful of what you say.

OC:
[cross talk]Yeah. What?

Patricia:
I said: "Please take a little bit of butter off the biscuits; there's too much on there." "It's not too much! Say: 'It's not too much!'", say: 'It's not too much!'" And she was in my face!

OC:
Mm.

Patricia:
And, she was about to attack, so she grabbed the other half avocado pear that was left. And she threw it at me. So, of course I was trembling and shaking, I was trying to be okay. Let her think I'm okay, I was trying to be in control. To make her think I'm in control even if I'm not. And then, she was shouting and screaming at me that it's not too much butter. And I said, since... And she's looking like that avocado pear on the floor. And I'm very much on my nerves and I wanted to walk away from the kitchen. I wanted to walk out of the kitchen to get away from her but I was scared, because she does attack from behind.

training.

- Maternal fear.
- Trauma.
- Anticipating the worst.

Yes! So, she knew what she did. Sometimes I believed that Sue doesn't know what she's doing. But there I realised: She knew what she did. Because when I said that... That: "Daddy's on his way, now!" Although I knew he wasn't. I just said it, because I was getting scared.

OC:

Mm, mm.

Patricia:

"Daddy's on his way, he's just gonna fetch =other daughter's name=." (Speaking softly) She said: "Oh! You won't tell him, hey? You won't tell him." So I said: "I'm not cleaning that up." As where before I would've been on my hands and knees already.

OC: Patricia, what was going through your mind when she started cleaning it up?

Patricia: [cross talk] (raising her voice) I was scared! I was scared!

OC: Scared, scared. And when she started cleaning it up?

Patricia: I thought to myself: this child knows what she's doing.

22

- Dysfunctional parent-child interaction.
- Maternal attributions of intentionality - child's behaviour.

- Maternal attributions of intentionality of child's behaviour.
- Feeling scared w.r.t. behaviour.

- Parental stress increased because of child's behaviour.

was, the behaviour with Sue was unpleasant, we did our outmost to... Yesterday was okay, although... Everything we did was to suit her. Not ourselves.

OC: And then problem-solve and think a bit... I mean it is very difficult, but is there anything we can do to try and make its impact on you just a bit less pronounced? Uhm, it's no easy task!

OC: ...and maybe also, uhm, linking that with Sue's psychiatric diagnoses, currently. I did link up with =psychiatrist's name=. And I do think we need to make an appointment, because the diagnoses currently, uhm, necessitate the psychiatrist to see her quite urgently. I believe she's psychotic.

Patricia: Nothing, just the fact that I need to be able to cope with this. I can't, I can't cope.

OC: Ja.

Patricia: This whole weekend I'm thinking – I don't want this anymore!

OC: Hm!

Patricia:
The whole weekend. When I got up this morning: Is she gonna go to work today? How am I gonna cope if she's not going to go to work? Peter is

- Process: Put on agenda problem-solving to deal with behavioural outbursts.
- Agenda, focusing on psychiatric symptoms of Sue's behaviour - psychoeducation & follow-up with psychiatry [part of agenda of problem-solving].
- Burnout?
- Helplessness
- Been coping with Sue's problems for decades, but believes she cannot continue - pile-up of life stressors w.r.t. caregiving?
- Depressive symptoms

very busy at work. And I just don't want it anymore.

—

Patricia: You know, and then the thought comes to my mind: Shame, she is my child. And... you know? She gets a smile and say: "I love you, Mommy" And then it changes things a bit. It changes the way of thinking about it a bit. But at the moment...

—

OC: The problem with Sue's behaviour is, though, that if we look at the underlying thoughts, uhm, it still comes down to: If you're afraid that Sue might lash out at you, it's pretty valid.

Patricia: Hmm.

OC: It's pretty real. There's a pretty good chance that she might actually do it!

Patricia: Definitely.

OC: Mm, and then there's the catastrophising. And we spoke about this. Every time it happens you anticipate that the worst is bound to happen.

Patricia: Mm.

—

OC:
Mm, it's pretty valid, and... Was this related to increased seizures on Friday evening?

Patricia:

- Feeling sorry for child.
- Positive: protective towards child.

- Process: OC validating P's experiences and setting the scene to explore catastrophizing.

- Child's behaviour linked with child's physical health.

I think so! I think so because we heard her having two seizures...

—

Patricia: Ja. We hear that sound and =husband's name= still said to me, it was in the early hours of the morning, ?we woke up? because we sleep light... We heard it. I didn't go back to the room because by the time I went there she would've most likely been back onto the mattress. Before, I used to run to the room. No matter how many times per night she had a seizure I was there. So! (sighs) I do realise there's nothing I can do about that. You know, to make her comfortable. She's so *deurmekaar* (confused) she doesn't know I'm there. If I'm wide awake then I'll, wide awake – wide awake enough, then I'll [inaudible segment], you know?

—

OC:
So that's where the TV comes in. And-and, you know, somebody talking to her from the TV...

Patricia:
Hm!

OC:
That's similar, you know, but you need a psychiatrist to look at it as well.

Patricia:
Ja.

OC:
There's also pronounced autism with Sue. That's ongoing, it's been like that since a young age. So, for our purposes, and again, 30 years ago they

- Helplessness w.r.t. seizures.
- Interrupted sleep due to seizures.

- Psychoeducation: role of autism, epilepsy, post-ictal psychosis and mood on Sue's behaviour. (just an example or excerpt of much longer discussion with much more detail)

wouldn't have necessarily diagnosed autism.

—

OC##

She continues [inaudible segment]. Okay, so to cope with this I think the very first we need to, very consciously, very deliberately focus on is to keep an eye on especially bad attacks and signs of hypomania following seizures like the weekend.

Patricia:
Mm, mm.

OC:
It might only persist for a day or two, but it means that it might be a very rough, rough time for that day or two.

Patricia:
Ja! I do believe that.

—

OC:
So in your mind, if you think of Sue's behaviour, Sue, without spending too much time thinking about the issue that I'm going to ask just now: Uhm, for how many hours of the day, and for how many days of the week are you typically almost like under threat because of Sue's behaviour?

Patricia:
(silence) (Exhaling). It's only four days a week, sometimes three.

OC:
Yeah.

- Process: psychoeducation = behaviour is worse after nocturnal seizures; increased symptoms of psychosis - trying to increase Patricia's sensitivity to cues of deteriorated behavioural functioning in Sue to mitigate impact of helplessness.

- Cognitive distortion: generalisation that fuels apprehensive expectation - Sue's behaviour could explode at any point in time - minimising significance of cues and heightened irritability following increased frequency of nocturnal seizures.

Patricia:
Mm.

OC:
So, it's not the whole week?

Patricia:
Uh-huh. There's been times when she's been two nice weeks.

OC:
Yeah?

Patricia:
Very seldom, but there is times, like we're waiting for it to happen.

—

Patricia: It's like, she'll kick against something. She always kicks against something. And she's got all her little, she's putting all her little cell phones that she cuts out, all the little [inaudible segment] in gift bags. And it's all round up next to her bed, it's all facing a certain way. ?It's the way she wants it? So, when she's having a fit we hear these things fly

—

OC:
Yeah, yeah. The generalisation and inherent danger here is that...

Patricia:
[interjection] Yes! Yes. Ja.

OC:

- Child's behaviour: autism-related traits - obsessionalities at baseline.

- Process: cognitive distortion: I must be on guard all the time - generalisation; looking at which amount of time Sue is at home.
- Feeling constantly vigilant.

...that your mind might be generalising it to “all the time”. That is what happens.

Patricia:

Yeah. Like I’m sitting here I’m just so wound up, you know? Like I should be relaxing because she’s not around!

—

Patricia: I know that. I do know only to get myself out of that space and... she’s not there all the time. She can’t do what’s she’s doing to me, cause I’m allowing it. And I got to learn how to not get into that... rut that I’m in.

—

Patricia: She’s strong, she’s powerful, she doesn’t only hit you – she’ll kick, she’ll throw, you know? You don’t know what’s gonna happen. How am I going to get it. So, ja. So, I don’t know if I’m going to get kicked, or hit, or if she’s gonna throw something against my head, or... and just the, the scary part.

—

OC:

Mm. And if it happens, I mean – does she hurt you to the point when, when you had to...?

Patricia:

No, I didn’t have to go to the doctor, or hospital, or anything. But she’s bitten us, she’s thrown us with stuff...

- External locus of control.
- Stuck in a rut w.r.t. caregiving and anxiety and stress about caregiving.
- Modifying belief that Sue could act out all the time.
- Intermediate assumption: I'm allowing her to be aggressive towards me (opposing beliefs that I am helpless).
- Scared of severe aggressive behaviour towards her.
- Parental stress because of child’s behavioural difficulties.
- Decatastrophising - how bad has she hurt you?

OC:

Ja.

Patricia:

In her anger she'll grab our arm and latch on and bit you and hurt herself.

So, ja. But I do realise, that by talking now it has come to my mind, I do need to look at it in a lighter note. But I get so round(ed) up. I don't know... I think I can. If I work on it I suppose I could. I don't know.

—

Patricia: We need to give her, her own way. Even to, for example this morning. Every day she takes 2 milkshakes to work. She wanted =husband's name= to go and buy the milkshakes before he took her to work this morning. So he said: "But we're going to stop at the shop. We can stop at the shop. I would've gone in for you and buy." Usually she would stop at the shop, go in and buy the milkshake. But she wanted him to do it this morning. And I mean, it was so unnecessary but he did it to keep the peace.

—

OC:

What is..? I do want us to just focus a bit on what's going through your mind when Sue is lashing out at you. What are you thinking about?

Patricia:

Is she gonna hurt, is she gonna hurt because I'm getting really fearful lately. Is she gonna hurt =husband's name=?

OC:

=Husband's name=? To what point is she gonna hurt =husband's name=?

- Keeping the peace by giving in to unreasonable requests.

- Catastrophising.
- Automatic image of husband having a heart attack.

Patricia:
Is he gonna have a heart attack? Because he stresses so much: "Please Sue, stop it Sue!" And he's shouting: "C'mon baby, calm down!" And she's going ballistic and he's begging her from deep down. Begging her: "Stop now! Don't hurt yourself! "

Patricia: So what went through my mind was: Oh, my God, she's gonna hurt =husband's name=. Because I just heard things making a noise. Things going fly. I didn't see it, but that's what I heard. I didn't go to the room. I sat on the bed and I froze. I thought: God, don't let her hurt herself; don't let her hurt =husband's name=.

Patricia: Walking on egg shells, and Sue is saying: "I'm not going to work until you buy my milkshakes."

OC:
And as long as fear, and very valid fear, and anxiety prevent both you and =husband's name= from actually contesting Sue's immediate gratification of needs, it's not really viable to embark on that.

Patricia:
Mm. Ja.

OC:

I mean, that is why we're just thinking a bit about the worst-case scenarios and things. I think you have started to do it by not cleaning up after her

- [illegible]

OC:

Mm.

Patricia:
So he keeps me away...

OC:
Yeah.

Patricia:
...and I... my argument with him is: are you allowing her to speak to me like this?

—
Patricia: Meantime, I don't know! I know he's not hurt me, he's not going allow this. But I'm so angry at the moment, I'm lashing out at him because she's so rude to me and he's not doing anything about it.

—
Patricia: And then put on the computer, and there was a beautiful, uplifting message. You know, trials and tribulations, things that I go through that made me feel better. So, thank you God, that was for me. And I felt a little bit better. And I could get up there and carry on in the kitchen. So, ja. I can't always get away from it, but I try move away from it and do something that's gonna take my mind off. It's not take, it doesn't take my mind off of what's just happened, but instead of sitting pondering about what happened, fretting about what happened, I try and do what, the next best thing.

—
Session 6

- Maternal anger.
- Anger towards husband.

- Coping through distraction.
- Positive reappraisal.

<p>OC: Okay, uhm: How was the week?</p> <p>Patricia: Sue wasn't too bad this week. There was no incidents that was upsetting in any way.</p> <p>OC: Yes.</p> <p>Patricia: (sighs) [inaudible segment] there was nothing I could put my finger on; let's say I was stressed to the max.</p> <p>—</p> <p>Patricia: And also . . . it's because we did what she wants us to do. Not that it's [inaudible segment], it's going to gonna be not good for her health or it's gonna hurt her, we did to keep her happy. (Long silence). But she wanted to do (clear throat) . . . Pardon, she wanted (clears throat), sorry, the usual braai (barbeque); go out to the Spur (a restaurant). As much as we didn't feel like it we did it. —</p> <p>Patricia: I suppose (if) we said we're not going, she would've kicked up a fuss, a big fuss.</p> <p>—</p> <p>Patricia: And it's not on! You know?</p> <p>OC: Yes.</p>	<ul style="list-style-type: none"> • High levels of parental stress and depression even though child's behavioural outbursts were minimal. • "Stressed to the max." - cognitive distortion of magnification. • Attributing child's improved behaviour to Patricia and Peter giving Sue her way. • Cognitive distortion: Catastrophising • Frustrated and angry with self for "keeping the peace" by not being assertive.
--	---

Patricia:
Not on! We do it to please her, to keep the peace.

—

Patricia:
(Long silence). I can't say... You know, I'm stressed, a really stressed out person. So I can't say it's gonna be any better, I don't know! But I don't, for the week that stressed about what happened this week.

OC:
Mm. Mm.

Patricia:
But I'm always a very stressed person, even when driving.

OC:
Ja.

Patricia:
I'm panicking already for the cars that's not even gonna come past us. So I am a stressed out person!

—

Patricia:
Last week I was feeling like: down, down, down. You know? Irritated, and miserable, and... (sighs) stressed. I don't feel as bad as ?(then)?

—

- Generalised anxiety - constantly worried about possible mishaps, in this case motor vehicle accidents.
- Apprehensive expectations; feeling on edge.

- Depressive symptoms.

- Lower motivation to do homework - I should have explored this with her in

<p>Patricia: Ja, ja. I supposed I have to do. Ja, I know. I didn't bring everything.</p> <p>—</p> <p>Patricia: When the DVD went flying with everything. And I wasn't that stressed. I sat on the bed, I was stressed, but not that... ja. Panicked.</p> <p>OC: Mm.</p> <p>Patricia: Ja. I sat there and I thought: Should I go, shouldn't I go? [inaudible segment] Like so now, I managed to keep back a little bit. Which I don't know... It seemed okay, because maybe it didn't get bigger. I don't know! (sighs) Maybe you can suggest to me how to go forward?</p> <p>—</p> <p>OC: Last week we also covered a bit that, you know, even though – and =husband's name= is supporting you so much –</p> <p>Patricia: Ja.</p> <p>OC: ...the type of support is not always optimally supportive. Have you given that a bit of thought?</p> <p>Patricia: I have given that a lot of thought! The way he's supporting the situation</p>	<p>more detail.</p> <ul style="list-style-type: none"> • More thoughtful about what she is doing to manage behaviour. • Uncertainty w.r.t. management. • Intermediate assumption about husband's giving Sue her way: If we don't give Sue her way, it will be ten times worse. • Ambivalent about the support she receives from Peter to manage Sue's behaviour.
--	--

with Sue... If he didn't do that, I've been thinking about it, maybe we didn't be so protective. It will be 10 times worse!

—

Patricia:
If he had to stand back or maybe walk away, I would've beat Sue, I would've hurt her.

—

Patricia: 'Cause a lot of times things have been going through my mind... Not the past week. (Long silence) Give her a couple of tablets. She can go sleep for a week. Really!

—

_ Patricia: So, you might say that he switch(ed) off, but he doesn't switch off and ignore her! He somehow doesn't get the way I get . . . I get completely stressed, anxious, angry . . . Very angry!

OC: Yes.

Patricia (sighs): There's times where, uh . . . There was some occasions where she gets so . . . I want to hit the head off her shoulders! The thought comes to my mind.

—

Patricia:
And he made her turn over and he smacked her backside, which is weird today when I look at it because she's a big woman!

OC:
Yeah.

- Maternal anger towards child.
- Rationalising husband's acquiescence.

- Wanting to escape from child.
- Maternal anger and frustration.

- Maternal anger.

- Denigrating child.
- Inappropriate management of behaviour.

Patricia:
And she said: "Sorry, Daddy! Sorry, Daddy!" And he gave her a couple of smacks. And she shouted: "Sorry, Daddy! Sorry, Daddy!" And she turned around, a-and he walked back. And she I-lifted up her leg and she kicked him flying. You know, he's small. And of course he did go fly. So he tried to give her a hiding (phone starts ringing in background). Thinking, you know, like a small child: Give her a hiding, maybe it'll work. And that was the first time ever! And, uhm, at many times I will say I ?(will)? want to smack her through her face!

—
Patricia:
I've been thinking about it and I was angry with him! Not because of anything else. Not really him. It wasn't really him that I was angry with. I was more angry at Sue because he won't give me my own way.

OC:
Mm. Mm

Patricia:
I want to reprimand her.

OC:
Mm.

Patricia:
Not always... there's some times I want to try reprimand her for what she's doing. But I do realise – we spoke about it, =husband's name= and I – and I do see that's there's no ways we're going to get through to her. Even with a smack, or a hiding, or saying to her: "Carry on, break what you wanna break!"

- Anger towards husband.
- Anger towards Sue.

- Cognitive distortion: Polarised thinking: There is no way getting through to her. Behaviour: therefore, give Sue what she wants - keep the peace.

<p>—</p> <p>OC: ... you had certain beliefs about the way =husband's name= treats Sue.</p> <p>Patricia: Mm. I was angry.</p> <p>OC: And that made you feel angry.</p> <p>Patricia: Hm!</p> <p>OC: Uhm, what do you think were your beliefs about the way that =husband's name= treat Sue before?</p> <p>Patricia: He's giving her, her own way.</p> <p>OC: Okay, so could you put that for me in a sentence?</p> <p>Patricia: I felt that =husband's name= was giving Sue her own way.</p> <p>OC: Okay, so I'll just write this down: =Husband's name= gives Sue her own way.</p>	<ul style="list-style-type: none"> • Identifying automatic beliefs.
---	--

<p>Patricia: And I'll say to him, she's nothing but a spoiled b***h! You're spoiling her.</p> <p>—</p> <p>Patricia: But now I'm angry! I'm angry for what she's doing and saying.</p> <p>OC: Okay. Feelings. In terms of feelings. Let's focus on the thoughts. So, we'll get to the feelings.</p> <p>Patricia: Okay, or the thoughts. Ja.</p> <p>OC: Okay. The way =husband's name= treated her made you think about levels of support: =Husband's name= is doing this so I am thinking that he is not..?</p> <p>Patricia: Spoiling her, giving her, her own way.</p> <p>OC: Ja?</p> <p>Patricia: He's not going to make her realise that what she's doing is wrong.</p> <p>OC: Okay, can I write that down?</p> <p>Patricia: Yes.</p>	<p>Maternal anger. Low levels of maternal satisfaction.</p> <p>Maternal anger.</p> <p>Disagreement with husband about management of Sue's behaviour.</p>
---	--

OC:
=Husband's name= is...

Patricia:
That was my thoughts.

OC:
Ja. "wrong-he-is"

Patricia:
Not making her realise that what she's doing is wrong. That's she's not gonna learn that she can't treat us like this; that she can't behave like this.

OC:
"that"

Patricia:
Like she's wrong to treat, like you know?

OC:
Ja!

Patricia:
Ja. Like ?(soft)? and "Shame" and "Okay, Sue" and that type of thing. Pacifying her all the time!

OC:
Okay, I'm gonna write that one down: Pacifying...

Patricia:
all the time.

<p>OC: (Long silence) Four. I think we can start working with them. And those beliefs led to feelings of..?</p> <p>Patricia: Anger towards him and her. But a lot towards him because now I can't deal with her the way I want to deal with her. Or that moment I wanted to reprimand her.</p> <p>OC: Yes. Yes.</p> <p>Patricia: You know? Ja, for that I was angry-angry towards him. As well as the anger towards her stays. We were, obviously so angry towards him I won't talk to him for a day or two.</p> <p>AND LATER</p> <p>OC: There's 5 beliefs or thoughts going through your mind. And then the following one is emotions, and you have emotions of [inaudible segment].</p> <p>Patricia: [cross talk] [inaudible segment] ja. Sad, angry. Very angry and sad. Disappointed.</p> <p>OC: (writing down) Disappointed. Okay, so – and the one we also mentioned as bitterness.</p>	<p>Anger towards husband and Sue.</p> <p>Maternal depressive symptoms. Maternal anger. Disappointment with husband.</p>
---	---

Patricia:
[cross talk] Because it's incidents like that for me...

OC:
Uh-huh? (Louder, pronounced, expectant)

Patricia: ...when something like that happens, and it happens so often:
[inaudible segment] and we work this out.

OC:
Ja.

Patricia:
Because it's a constant thing.

OC:
Okay.

Patricia:
This weekend was wonderful, like I said!

OC:
Mm.

Patricia:
Because he gave her, her own way. There was no drama. He gave her,
her own way.

—
Patricia:

- Thought suppression (context: standing up and telling husband that she wants him to stop pacifying Sue - anxiety provoking - repress it immediately.)
- Thought suppression and changing the subject.
- Slipping in her financial worries.

We could've rather stayed at home. There're things that could be done in the house; there's money wasted this weekend.

—

OC: Angry. Okay. Now, let's explore the thought, leave the feeling just there for a moment. Let's explore the thought. The thought is usually indicative of other things as well. =Husband's name= give Sue her own way. Uhm, what-what does it mean to you that =husband's name= gives Sue her own way?

Patricia:

It means that we are not dealing with the situation like we should. In the better way. In other words, he is giving her, her own way. And it's gonna happen over and over again, because this is a behaviour which Sue must get her own way.

OC:

Yes.

Patricia:

So instead of trying to break that pattern, we're not, we're just: we're giving her, her own way!

OC:

Yes.

Patricia:

And for me, it's like getting angry with him – why're you giving her, her own way? I can't deal with this; I must reprimand her because this must stop. We must do something to make it stop. It's been going on for too long and as she's getting older, it's getting worse. So, that is why I'm angry with him...

- Cognitive dissonance.
- Insight that negative reinforcement through giving-in to Sue's unreasonable requests.
- Pile-up of caregiving stressors.

—
Patricia:
(Long silence) If he didn't give her her own way, it's not fair that he should give her her own way. But then he didn't. (Door slammed in background, people talking in corridor in background.)

OC:
Mm.

Patricia:
[inaudible segment] I don't think I'll be able to cope with the consequences all the time.

—
OC:
So, you were lying in bed, hoping that she's not gonna call you, worried that, you know, what is going to happen?

Patricia:
Mm. What's gonna happen? What is going to happen? That was what I was thinking.

OC:
[cross talk] That's a thought.

Patricia:
Ja.

OC:
What's gonna happen? And surely you must have..?

- Intermediate assumption: Husband giving Sue her own way to keep the peace. If he does not, I don't think I will be able to deal with the consequences (of severe behavioural outbursts). Thus: If Peter does not keep the peace, I will not be able to cope with Sue's behavioural outbursts that will follow if he does not keep the peace.

- Long excerpt: Event - Patricia in bed not going to Sue to say goodnight and to tell her daughter that she's going to bed (avoidance of uncertainty).
- Uncertainty created by changed behaviour.
- Patricia continues to worry about this, uncertainty whether Sue will demand that she changes the DVD player.
- Simultaneously, Patricia realises that she must stop giving Sue her way the whole time - (I interpret this as insight into impact of negative reinforcement).
- Worried until she changes her belief from what if she calls me to change the DVD (uncertainty) to (So what if she calls me?) - the last thought implying decatastrophising, i.e. is it that bad to be called?

<p>Patricia: [cross talk] [inaudible segment] The day's gonna end up peacefully? Are we gonna get in bed peacefully tonight? That was what I was thinking.</p> <p>OC: And how speci... That's the thought: Are we going to go bed peacefully tonight?</p> <p>Patricia: Mm.</p> <p>OC: And surely, somewhere in your mind you might've thought about, uhm, 'not peacefully'?</p> <p>Patricia: Oh yes! Definitely!</p> <p>OC: So, through your mind was going?</p> <p>Patricia: Is there going to be drama tonight?; Am I gonna be called?; How many times?</p> <p>OC: There is your belief, there is your thought. Will Sue . . . ?</p> <p>Patricia: [cross talk] I was laying there, laying for it to happen. Is she gonna cause a scene tonight?</p> <p>OC:</p>	<p>Expecting the worst – catastrophising.</p>
--	---

There's a thought! Is Sue gonna cause a scene tonight?

OC:
So you see, uhm: so often your thoughts are masked as emotions?

Patricia:
Mm!

OC:
That you think: I thought I was worried.

Patricia:
Mm.

OC:
But you have to explore that to get to the thought and the belief.

Patricia:
[cross talk] Ja.

OC:
Now we have it: Is Sue gonna cause a scene tonight?

Patricia:
Mm.

OC:
Okay, and that made you feel worried.

Patricia:
Yes.

OC:

<p>Okay. And then: Event, belief, emotion, behaviours.</p> <p>Patricia: [cross talk] Mm. Mm.</p> <p>OC: That informed your behaviour. So, because you were worried: What would you usually have done?</p> <p>Patricia: I would've, would've preferred to do what I usually do, is going to Sue and say: "Good night, Sue, I'm going to bed now. Is there anything else you need?"</p> <p>OC: Mm.</p> <p>Patricia: "Otherwise you'll need to get up and see to it yourself."</p> <p>OC: Yeah.</p> <p>Patricia: Then I would've gone to bed feeling a little bit better.</p> <p>OC: Mm.</p> <p>Patricia: Not to say that she's not going to call.</p> <p>OC:</p>	<p>Avoidance of uncertainty.</p>
--	----------------------------------

<p>Mm.</p> <p>Patricia: Or want our attention or my attention. Uhm, ja.</p> <p>OC: Okay. And yet that would also activate these systems of: I am making it worse, because of in the future she's gonna do more of this.</p> <p>Patricia: [cross talk] Yes. Yes.</p> <p>OC: You see? So, by instigating the one behaviour...</p> <p>Patricia: Ja!</p> <p>OC: ... to reduce your worry, you are reinforcing the other behaviour, or the other emotion of worrying about future events.</p> <p>Patricia: Yes! Yes! [cross talk] It's constant.</p> <p>OC: It's constant.</p> <p>Patricia: It's constant.</p> <p>OC: And that is very draining. I mean, that is just debilitating.</p>	<p>Uncertainty avoidance.</p>
--	-------------------------------

Patricia:
Yes! It is.

OC:
Okay, so this time around you didn't... you didn't get up. And..?

Patricia:
No, I didn't. She came to me. An hour later, she came to me and said:
"Yes, and what's happening?"

OC:
Yes. And what was going through your mind when you decided you're not going to get up?

Patricia:
I smiled inside myself and I thought: Ah-ah, what's going to happen now?
Please... And I actually said a prayer: *Please God, let this be, let this end up to be a peaceful night.*

OC:
[cross talk] Ja.

Patricia:
And I did have that fear in me, like: Ooh, now like she's gonna...
Sometimes she'll pull the blankets off. What the he... Like, get up! Why are you in bed? But, it was...

OC:
Peaceful?

Patricia:
Peacefulish. Peacefulish.

<p>OC: [cross talk] You modified your belief of, uhm, I think Sue is gonna make a scene tonight.</p> <p>Patricia: Mm, mm.</p> <p>OC: To... You added something on.</p> <p>Patricia: Ah.</p> <p>OC: What did you add on, Patricia, that made you go through..?</p> <p>Patricia: What do you mean?</p> <p>OC: I think Sue is gonna make a scene tonight. But, this time..?</p> <p>Patricia: I'll deal with it if it happens.</p> <p>OC: Okay. How did that make you feel?</p> <p>Patricia: A little bit apprehensive, I wasn't...</p> <p>OC:</p>	<p>Restructured belief from former beliefs.</p>
--	---

<p>Of course.</p> <p>Patricia: You know, it didn't make me feel good, because I was waiting for it. I was watching a movie, but I was waiting for her.</p> <p>OC: Why did you go ahead if it made you a bit apprehensive?</p> <p>Patricia: Because, I thought: I need to watch this movie, I need to do something for me. She's sitting there inside and she's gonna ask for that cuppa tea.</p> <p>OC: Yes?</p> <p>Patricia: Which is already been made.</p> <p>OC: Hm.</p> <p>Patricia: She's going to ask me to change the DVD channel in her room.</p> <p>OC: Yeah.</p> <p>Patricia: Uhm, I'm gonna close my door so that I don't hear that music. And if she calls me, it's going to be a big problem if I don't hear her straight away. But you know what? Something at the back of my mind said to me: So what?</p>	
--	--

<p>—</p> <p>Patricia: And then, you know, the thoughts that is going through my mind: Shame, poor =husband's name=! Why must he go if she shouts again?" All this is going through my mind, and then still thinking: "Agh, you know? Let it happen when it happens.</p> <p>—</p> <p>OC: Because you were smiling when you're saying it, so..?</p> <p>Patricia: Well, I thought I better watch my movie!</p> <p>OC: And it made you feel?</p> <p>Patricia: Good! It made me feel a little bit, ja.</p> <p>OC: [cross talk] A little bit more?</p> <p>Patricia: Better, because I'm gonna watch... I'm doing what I want to do!</p> <p>OC: Okay! So there we go. You know, the same event?</p> <p>Patricia:</p>	<ul style="list-style-type: none"> • Automatic thoughts present in same situation: not getting out of bed - uncertainty escalates and tension because she gets anxious due to uncertainty. • Act of assertive parenting. • Same event - guided discovery. • Automatic belief- I am doing what I want to do, but I am worried about what's gonna happen if I want to do it.
---	--

<p>(Laughs) And a different [inaudible segment] because I don't usually do that!</p> <p>OC: Yes?</p> <p>Patricia: I don't usually do things for me.</p> <p>OC: Okay? You felt better, because...</p> <p>Patricia: [cross talk] But I was <i>sugging</i> (sighing) in case something's gonna happen! (Laughs)</p> <p>—</p> <p>OC: Mm. So we now know... it's almost like a stratified belief system: On the one hand we have the almost self-governing rule of <i>We need to give her her own way, because otherwise drama will break loose.</i></p> <p>Patricia: Mm.</p> <p>OC: And then as an opposite thought there is: <i>By giving her her own way, we are making things worse.</i></p> <p>—</p> <p>Patricia: And this morning she got done for work, she got dressed, she got washed. She made up, she always makes up her bed and she changes her bedding</p>	<p>Double bind - stratified belief system. Need to keep the peace to prevent outbursts vs we are making it worse by keeping the peace.</p> <ul style="list-style-type: none"> • Positive affection displayed towards Sue.
---	--

every day. I think it's also another problem because you don't change all your bedding every day. But she did all these things. And... I asked her: "What you're gonna have for breakfast?" And I always ask her. And she said: Provita biscuits. I said: "Okay, fine." And, she was ready to go. =Husband's name= didn't have to wait and, "Come, Sue, come, Sue". Because everything went smooth. And I kissed her good bye and said to her: You've been so good today! You've been so good this morning!

—

Patricia:
When her music's soft at night, the next morning I'll say to her: "You know, Sue, Mommy slept so nice!" Because I ?(never)? heard your music!

OC:
And what does she do then?

Patricia:
Uhm, what does she do? She doesn't always answer me. She'll smile. Or her eyes will light up a bit. Like she'll... Her eyes will twinkle somehow.

—
OC:
You know, let's make it really difficult caregiving situations. You write down the event. You write down your thoughts that went with the event.

Patricia:
Mm.

OC:
Your feelings... Third column.

- Good parenting – positive reinforcement of desirable behaviour.
- Positive emotion displayed towards child.

Patricia:
Mm.

OC:
Your behaviour. And then: See if you can change those thoughts. So then you write the thoughts again. You look for evidence and stuff. See, it's a difficult exercise!

Session 7

Patricia:
It was no major hassles. I did a little bit of...

OC:
Excellent!

Patricia:
But I'm useless at this! You've explained it to me over and over. I tried to do it. But I'm getting the feelings and the behaviours and all that, all *deurmekaar* (mixing everything up).

OC:
That's okay!

Patricia:
There was two incidents... was Friday, past.

OC:
Uh-huh?

Patricia:
Friday morning and then Saturday. But obviously... I think I've got it all

- Homework assignment.

- Lacking confidence to do homework right -her DTR was correctly and accurately captured, suggesting thoughts of: This is too difficult for me, and perhaps: I am inadequate.

wrong again.

OC:

Okay.

Patricia:

But just... Two big things that happened on the... like big outbursts that happened with Sue. And otherwise, I didn't put that down. But otherwise it was just the repeating. And repeating. And then she was re-be... for example, Sunday was Mother's Day. I invited all my family.

—

Patricia:

So Sunday evening at the supper table I actually wrote it down: The supper table she's asking me: "Mommy, uhm, who is coming tomorrow?" Now this is now about the 20th time for the day.

OC:

Mm.

Patricia:

So I tell her. Now I'm rattling all the names of for her and she's saying: "Say it again! Say it again!" And I tell her: "Okay, Sue, we're mentioning all the names." (Clears throat). And I'm repeating it, she's saying: "Say it again." So I said to her: "Okay, Sue, you tell me now." She mentions all the names and then she's... I said to her: "Okay, now you can stop and carry on eating! Because we must not talk like this at the supper table. I explained it to you, you know?" Here =husband's name= starts: "You know..." And he repeats everything that Sue's asking. She doesn't stop. Because she looks at me, but before =husband's name= started, she looked at me and she said: "Why is your face like that?" And now automatically, she can see I'm getting... upset.

- Parental stress due to repetitive behaviour.

- Husband overriding caregiving decision.

<p>—</p> <p>Patricia: She says: “Why is your face like that? Why do you look like that?” So, I’m getting upset! But I try not to show it because we are at the supper table. And ?(with)? that, =husband’s name= starts repeating the questions. She asks, she asks me again: “Now who is coming for supper?” “=Sister’s name=, and =other sister’s name=". And she mentions all the names. And =husband’s name= is saying: “Yes, Sue, ‘sister’s name= and =other’s sister’s name='. And it was just too much for me!</p> <p>—</p> <p>Patricia: It was really too much for me, I found it most upsetting. And I said: “Sue, we cannot eat like this, please stop!” And... it’s like =husband’s name= pushed his food aside. I just got up from the table and I walked away. And I burst into tears!</p> <p>OC: Yes, okay!</p> <p>Patricia: ‘Cause I can’t anymore!</p> <p>OC: Ja, I’m with you!</p> <p>Patricia: That was Saturday evening. It didn’t stop. I managed to get away. I sat in my room for half an hour. And then she came back to my room and she asked again: “Now who is coming tomorrow, Mommy?” But she looks at</p>	<ul style="list-style-type: none">• Repetitive questions and obsessional behaviour as causative agents of parental stress.• Husband "saving the peace" by giving Sue her way.• Inappropriate family support from husband’s efforts to keep the peace.• Impact of child's behaviour on maternal mood.• Helplessness.• Autism-related problem behaviour: child.
--	--

me and she's... like she's looking for my facial expression.

—

Patricia:

And that was like big. Because I thought it bloody go to my head and I just couldn't anymore. I thought: No! This is... You know? So, it was just one of the things the weekend. And of course, Friday morning, because she was at the hospital Thursday for a check-up, she decided she's not going to work Friday morning. (Silence). And, she woke up the normal time... (inaudible segment) "I'm not going to work today."

OC:

Mm.

Patricia:

"My stomach's sore." And it was about: "My throat is sore." And then she's... (Sighs) And there again... My first thought was: how am I going to cope with this child today? We had the whole day at the hospital and you know what the hospital story is like?

—

Patricia:

And I started getting anxious and she's crying. And then she started screaming: "I'm not going to work! I'll show you I'm not going to work! You're not my boss!" And da, da, da, da, da! You know your normal...

OC:

Mm.

Patricia:

And I walked away and I went to the toilet. And I sat in the toilet. And just

- Parental stress due to child's acting out behaviour.

- Anticipating problems if not apprehensive expectation.

praying: Please God, let her go to work today! And that's all I've been doing lately... Just praying for peace!

OC:
Ja!

Patricia:
But I can't... (Tremor in voice, sighs). I'm tired, I'm sick and tired of it! Really!

—
Patricia:
And I don't know if this is... upsetting me because I'm talking about it! I don't know! =Husband's name= and I are talking... about his side; what he's doing and what I am doing. And we both feel we can't... He can't stop what he's doing. He is trying to pull away, but he-he-he's... to leave me alone with Sue. 'Cause he can see I can't cope. (Tremor in voice). But I'm asking him to like... (Sighs) ...let go a little bit! Maybe also walk away.

—
Patricia:
So he's feeling worse, maybe. I'm not saying he is, but he could be feeling worse than what I'm feeling. It's just two incidents this week. Other than that Sue was okay. Just the repeating with time. ?(Running)? she didn't have any sleep last night because she was laying laughing at the TV... from 04:00 this morning! And of course when she got up... She didn't get up, I mean... When she was up, she didn't actually wake up this morning. She got out of the room, she was tired! She came into my room and she sat on the end of the bed. (Silence) And she's asked: What time are you fetching me today? Repeat of that about twenty times. And she had her breakfast, got dressed... (Long silence) And I just prayed that everything

- Pile-up of caregiving stressors.
- Helplessness.
- Coping by confrontive coping – discussing her concerns with Peter.
- Wanting to be more assertive towards Sue but lack of confidence from both whether new behavioural management strategies would work.
- Low sense of parental confidence; low parental self-efficacy.
- Coping through religion.
- Imagery of negative mood and helplessness.
- Child's mental health and impact on her behaviour: night-time disturbance.

runs smooth. And of course she had her breakfast and then to work which was... a relief! But like I can only say it get me feeling... At the moment I'm feeling... um, tired. Tired, tired, tired of it! (Tremor in voice).

—

OC:

The one thing I do want to put on the agenda today is that incident at the dining room table where you actually stood up, or got up and had to walk away.

Patricia:

I had to. Because I couldn't eat and the tears were in my eyes already and I didn't want her to see me crying.

OC:

Ja. Shame.

Patricia:

And my other daughter was also at the table. She was also at the table. You know? And it's unpleasant!

—

Patricia:

If she says an ugly thing to me or a horrible thing to me. Sometimes she says to me: "Look at you, you clot! Look in the mirror! Look at the..." (Laughs) You know? But I don't... I don't, um, take it to heart because she can't... She doesn't mean it.

OC:

Mm.

- Maternal depressive symptoms
- Process: Agenda: incident at table.
- Child's behaviour embarrassing Patricia in front of another family member (tentative).
- Dysfunctional parent-child interaction: child ridiculing parent.
- Thought repression to alleviate anxiety?
- Positive description of child or undoing?

The repeating, repeating, repeating all the time. And she wants me to answer. And I repeated it throughout the day over and over. And here we're sitting eating and... (sighs) Ja!

OC:
Repetitive, you know, statements made?

—

Patricia:
[cross talk] Because I'm already p****d off at Sue, now I got angry at =husband's name=! I looked at him, I thought now... I didn't say it! Because I dare not say something at the time because Sue will... Then she's... How can I explain to you? (Long silence) Plays the one against the other.

—

OC:
Bear with me! So thank you. When-when you were angry with him, what were you thinking about?

Patricia:
Why the f*** don't you shut up?

OC:
Why the f*** don't you shut up? Okay. That's anger. (Long silence)

Patricia:
I was really angry with him! But when I sat in the room and I cried it out, I realised he was only trying to help.

—

- Maternal anger directed towards husband and daughter.
- Furious with husband. Anger.

<p>Patricia: Because she's not giving me a break. She's not stopping when I'm asking her to stop. She's eating at my brain.</p> <p>—</p> <p>Patricia: So I was feeling sad because this is my life, this is the way it is. And getting angry at her for not wanting to stop, but I was more angry at =husband's name= for what he... maybe he just contributed to it.</p> <p>—</p> <p>Patricia: I should... I can't say I shouldn't have been, because I did; I was angry with... towards him. And it happened, but I do realise that he didn't mean to do me harm. He didn't mean to upset me. (Silence).</p> <p>—</p> <p>OC: [cross talk] What the meaning of =husband's name= . . . ? Sorry for interrupting you.</p> <p>Patricia: Mm.</p> <p>OC: What's the meaning of =husband's name= stopping what you're doing by actually coming between your questioning and...</p> <p>Patricia: [cross talk] Because I asked... I said I'm not gonna carry on.</p>	<ul style="list-style-type: none"> • Constant vigilance - • Cognitive distortion - overgeneralising - P gets breaks when S goes to workshop; at night; when her behaviour is better. <p>Cognitive distortion: Overgeneralisation - this is my life. Depressive symptoms</p> <ul style="list-style-type: none"> • Cognitive distortion: Imperative thinking.
---	--

<p>OC: Uh-huh?</p> <p>Patricia: And he decided he will.</p> <p>OC: [cross talk] What does that mean?</p> <p>Patricia: Because Sue will make a whole big scene. To one of us, she'll say: "Say 'Yes!', say 'Yes!'" You know? And you'll repeat on and on and on! So, that's where he interfered. And he started carrying on, yeah.</p> <p>OC: What's the meaning of the interference?</p> <p>Patricia: To keep the peace, once again!</p> <p>OC: Okay, but you also basically wanted to keep the peace by walking away.</p> <p>Patricia: Yes, yes.</p> <p>OC: By him almost overriding what you're doing, what is the meaning of it? Why did he do it?</p> <p>Patricia: Because he's trying to keep Sue happy. He is just trying to... I don't know how to explain this. He's... (Sighs) Why is he doing this? (Long silence)</p>	<ul style="list-style-type: none"> • (Part of longer discussion) - why is husband opposing her management - dysfunctional interaction between husband and wife w.r.t. management; I was challenging her to think about their interaction and idea that daughter's behaviour is sole contributor to her distress (misattribution).
--	--

The only way I can see it is he's trying to keep her happy. He's trying to just do what she wants to be done.

Patricia:
I couldn't sit there; I couldn't deal with it anymore! I had to... I said, I go...
My head's swaying here! I can't deal with this. I was going dizzy. I had to
get away!

OC:
(Inaudible segment) What does it mean about the way in which
=husband's name= actually treated Sue, and by proxy, you? What's the
meaning of it?

Patricia:
[interjection] It's like encouraging her to carry on.

OC:
And?

Patricia:
[cross talk] That's what I felt; that's why I was angry.

OC:
Okay. Okay. So we are going down a bit.

Patricia:
[cross talk] (inaudible segment) He was encouraging her to... You know?
Not that he did it out of spite.

- Panicking
- Satiated.

- Downward arrowing – keeping the peace is not acceptable to Patricia – is husband then really keeping the peace?
- Therefore not really keeping the peace.

Maternal anger.

OC:
Mm.

Patricia:
That's why I came out of the room, not being angry with him. I realise he wasn't being spiteful to me, but I thought this man is also driving me insane!

—

Patricia:
[cross talk] Wanted her to! Yes, just... I've said already: "Stop now,Sue. We are eating; it's enough now!" And he could've also tried and said: "Sue, it's enough, stop now! Listen to Mommy, we're eating now!"

—

Patricia:
He... Ja. Why he interferes all the time, is it because..? He thinks... And I feel I also can't deal with her. I'm scared, but he was sitting there! So he could've also said... We could've done it together. He could've also said: "Stop now! Finish, we're eating!"

OC:
Ja.

Patricia:
We could've done it, together.

—

Patricia:
Because he just didn't want to... He can get on with it. Because he just... I

- Cognitive dissonance: wanting to become more assertive but prevented by husband and own fear of behavioural outburst.
- Lack of collaboration - inappropriate family support (perception of)
- Resentment and disagreement with husband about management of child's behaviour.

don't know.

OC:
What are you thinking about right now, Patricia? What's going through your mind?

Patricia:
Why can't you just be more firm..? And if the sh** hits the fan, okay! If she's gonna turn the table over because she want answer, okay! We've already told her. That's what I'm thinking at the moment. (Sighs)

—
Patricia:
I don't think it was an unreasonable... Just to say, for her to keep quiet while we're eating! She knows that she can keep quiet while we're eating. She's done it before.

OC:
Mm.

Patricia:
And she was just on that space where repeating all the time.

OC:
Was there any possibility that Sue would not have acted out if you actually said it and stopped it?

Patricia:
I do realise that there would've been a big possibility that she wouldn't have acted out. That's why I said: "Finish! No more! I told you!" So, I do know there are times. And I'm willing to take that chance!

- Using mood shift to make P aware of AT - she had confidence that she could be more assertive during event - realisation that she had confidence in her observation made her more relaxed.
- Cognitive dissonance: increased need to become more assertive towards Sue in the management of her behavioural difficulties.

- Parental stress because of child's behavioural difficulties (repetitive behaviour)
- Use of LAA: absence of clear cues to signify aggression but repetitive behaviour instead.

<p>OC: Patricia, there was just now a shift in your affect; a shift in your facial expression and your demeanour. You became much more positive.</p> <p>Patricia: Mm.</p> <p>OC: So something went through your mind just now when you were saying there was a possibility that... (inaudible segment).</p> <p>Patricia: [cross talk] (inaudible segment)</p> <p>OC: What went through your mind? Sorry.</p> <p>Patricia: That she might just realise: Carry on eating and say nothing more.</p> <p>OC: Okay, now how did that make you feel? The thought that...</p> <p>Patricia: [cross talk] Peace! More relaxed, I would say.</p> <p>OC: Okay.</p> <p>Patricia: At ease.</p> <p>OC:</p>	<ul style="list-style-type: none"> • Mood shift that signified realisation that she has parental agency and a measure of control; that Sue might not respond aggressively and unlearn acting out behaviour.
---	--

Okay. So now, if we take this possibility in consideration by you saying: "Sue, stop that's enough." That it would have been effective. Let's say there was an effective outcome.

Patricia:
Mm.

OC:
And then =husband's name= intervened and continued, you know...

Patricia:
Ja.

OC:
The pattern of, um, answering obsessional thoughts and thinking.

Patricia:
Ja.

OC:
Um, if it was, you know, a higher likelihood of a positive outcome: How does it make you feel about =husband's name='s behaviour and his decision to basically override your decision?

Patricia:
How would it make me feel? Then it would make me feel very angry.

—

Patricia:
And then... He will come, trotting along! And then he'll do what I just told her to do herself. And then that's where I get angry with him! And I'm already... (long silence) Ooh, I'm already fuming towards Sue. But working myself up, because she's stressing me out, I can't do it now, but... Ja! So

- Modified attribution - finally realising that she is not only angry with daughter's behaviour, but husband's management and overriding management strategies of behaviour. More balanced perspective when compared to earlier thinking and attributions.

<p>it's a lot of anger, and anger towards =husband's name=.</p> <p>—</p> <p>Patricia: We're not working together.</p> <p>OC: But is he keeping the peace? Do you think...</p> <p>Patricia: [cross talk] He is keeping the peace.</p> <p>OC: But is it peaceful when he does that?</p> <p>Patricia: It's peaceful because she shuts up, yes.</p> <p>OC: Okay?</p> <p>Patricia: Only that. But I'm still bitter.</p> <p>OC: Is-is the feelings of bitterness and anger peaceful?</p> <p>Patricia: No, not at all!</p> <p>OC: So is =husband's name= really keeping the peace?</p>	<ul style="list-style-type: none">• Realising husband is not keeping the peace but making matters worse with his management style.
---	--

<p>Patricia: By ?(noise)?, ja. But... there-there's no inner peace...</p> <p>OC: What-what-what does it mean to keep the peace?</p> <p>Patricia: Just give her, her own way so she can shut up. And we can carry on doing what we need to do.</p> <p>OC: But does the peace only relate to Sue? (coughs) Isn't it eventually for both?</p> <p>Patricia: ?(From the home, to the home)?, to everybody involved.</p> <p>OC: Mm. So by =husband's name= keeping the peace: does he manage to keep the peace with you as well?</p> <p>Patricia: (Long silence) No.</p> <p>OC: He's not keeping the peace.</p> <p>Patricia: He's not keeping the peace! Because... I'm... might've been quiet about it on Saturday and not angry towards him afterwards, but I am... (Long silence, sighs) You know, me and words or feelings: I'm resentful towards him!</p>	
--	--

<p>OC: Mm.</p> <p>Patricia: You know? Once again because... he jumped up, did what he had to do to keep the peace. And then I said to myself: Oh, thank God he did that! What could've happened.</p> <p>—</p> <p>Patricia: Yes! (sighs) I am disempowered. I am very much so.</p> <p>—</p> <p>Patricia: But, it's not all that helpful because... we could try and work this together. (Silence) And I might decide, ja, I rather keep the peace. But I feel there is, are times that she can... When "No" is "No".</p> <p>—</p> <p>OC: Yes! (Laughs) I mean, that is basically... If a child hears one of those ice cream trucks and he goes to his mom and say: "I want to have an ice cream, please." And you say: "No!" And child starts having a (inaudible segment) temper tantrum...</p> <p>Patricia: Mm.</p> <p>OC: And just to get the noise out of your head with the child having a temper</p>	<ul style="list-style-type: none"> • Husband is disempowering her within caregiving context. • VQ: Modified belief about keeping the peace and behavioural difficulties and husband's role in all of this. • Negative reinforcement explained through psychoeducation.
---	---

tantrum, you say “Yes, here’s the money, go and buy it!”

Patricia:

Ja.

OC:

That is what negative reinforcement means.

Patricia:

Yes! Yes.

OC:

Because you are not reinforcing the child asking the next time, the child would’ve asked anyway. What you are reinforcing is the efficacy of having a tantrum as a way of getting ice cream.

Patricia:

Yeah!

OC:

The next time, if you say: “No!” The child might actually cry more, have more of a temper tantrum.

Patricia:

Think about it. Ja. Ja. I hear what you’re saying about, um... I’m just hoping that Sue would just learn: Mommy’s not gonna do it!

—

OC:

If you take photos of all these individuals: =Sister’s name=, =sister’s partner’s name=, your other sister. What’s her name again?

- Problem-solving - using visual aids to replace repetition.

<p>Patricia: Um, =other's sister's name=.</p> <p>OC: =Other sister's name= . Um, all the people. (Phone starts ringing in background in another office). And you take the pictures, you have a card.</p> <p>Patricia: Mm?</p> <p>OC: And you laminate the pictures. It doesn't need to be fancy lamination, we can help you with that as well. You can use plastic paper as well.</p> <p>Patricia: Mm.</p> <p>OC: The stuff that you use to cover school books.</p> <p>Patricia: Mm.</p> <p>OC: And you paste everything onto a card.</p> <p>Patricia: Ja?</p> <p>OC: So these people are coming: =Sister's name=, =sister's partner's name=. And you give it to Sue . Will that in any way, um, reduce the obsession asking and stuff?</p>	
---	--

<p>—</p> <p>OC: (reads) Sue refusing to go to work. Screaming, crying, getting her own way. She was off Thursday. Thought: How am I going to cope if she stays at home all day, weekend? And then make you anxious...</p> <p>Patricia: Mm.</p> <p>OC: And scared...</p> <p>Patricia: Mm. That's how I felt.</p> <p>OC: It looks perfect so far.</p> <p>—</p> <p>Patricia: [cross talk] I suppose when I make up my mind: I have to do this; now I've got to be more brave.</p> <p>OC: Mm.</p> <p>Patricia: Be more assertive. Ja, you're right. Um, I suppose that if we changed it, I won't be that scared.</p> <p>OC: The thought came through your mind: Um, she's going to... I will not be</p>	<ul style="list-style-type: none"> • Second part of agenda: Going through homework exercise. Accurately done - can make connections - self-confidence - emotional reasoning? • P wants to increase assertiveness towards Sue.
---	---

<p>able to cope to an immediate feeling of: the worst is gonna happen.</p> <p>Patricia: Mm! Mm!</p> <p>OC: And that made you extremely scared. It's the same as when somebody holds a gun...</p> <p>Patricia: Mm.</p> <p>OC: It's the same reaction.</p> <p>Patricia: Mm.</p> <p>OC: Because your mind, in a way...</p> <p>Patricia: Ja!</p> <p>OC: Would... I think there might be images of Sue...</p> <p>Patricia: [cross talk] Yes! Yes! Yes.</p> <p>OC: (inaudible segment) Um, we... If you modify: It will be extremely difficult but...</p>	<ul style="list-style-type: none"> • Process: easily IDENTIFYING automatic beliefs, but difficulty in modifying them. • Focused on this - with lots of directive intervention, changing thought of I can't cope during the weekend to it will be difficult, but I will be able to cope.
---	---

Patricia:
[cross talk] I will cope.

OC:
Ja.

Patricia:
I will cope. Now I'm thinking about it, putting it that way. Deal with it as it comes.

Session 8:

Patricia:
I'm okay, my chest is all buggered up, otherwise...

—

Patricia:
What a wonderful week!

OC:
Really?

Patricia:
Honestly. Honestly.

OC:
Tell me more, Sue?

Patricia:
It was like... waiting... Actually waiting for the moment where there's gonna be a scene, or an unpleasantness. It was like heaven.

- Physical ill health reported as variable.
- Child's behaviour reported as improved

<p>—</p> <p>Patricia: Um, I can't think of (/a/) incident where I was upset with her... angry with her. As a matter of fact this week I showed her a lot of love, because I would say it started from... A whole week! A whole week!</p> <p>—</p> <p>Patricia: [cross talk] Yes. Yes. It never stopped since the day that the DVD player was given back to her on her birthday that she got the DVD. It hasn't stopped being playing and I think it could have a lot to do with my thinking. Because (inaudible segment). Okay, it's not one song, it's a whole DVD.</p> <p>—</p> <p>Patricia: [cross talk] Yes. Yes. It never stopped since the day that the DVD player was given back to her on her birthday that she got the DVD. It hasn't stopped being playing and I think it could have a lot to do with my thinking. Because (inaudible segment). Okay, it's not one song, it's a whole DVD</p> <p>—</p> <p>Patricia: Definitely less. There was nothing I could complain about Sue this week. I wasn't angry with her for anything. I just kept on telling her: "Mommy loves you," because... and I didn't say because. The reason I was saying that was because of her behaviour... the change.</p>	<ul style="list-style-type: none"> • Positive experience of caregiving. • Repetitive behaviour and obsession stopped. • Child's physical health change: Decreased seizure frequency. • Positive experience of caregiving – displaying more positive affection towards child.
---	--

And she has been lovable the whole week. But she'll come up to me, and give me hug, and say: "I love you, Mommy", and "I'm your child, hey?" You know, little things like that. And: "How many children have you got?"

You know, and she always asks me to say. No! The repetitiveness is still there .

Mm. It's not having as much of an impact on you though?

Yes. Definitely not.

I don't feel down. I did the suggestion, what you suggested: I've got myself a book . I even got =husband's name= to get him a book..

Ah, excellent!

We went to the bookshop on Friday morning.

Internal shift?

- More energy – started reading again – “delayed behavioural activation.”

OC:

What did you buy?

Patricia:

And we both started reading on Friday evening. And... I suppose I got the wrong book but it's okay! You know?

—

Patricia:

Ja! If it keeps her happy by saying yes, but when the time comes we'll... (long pause) change it and say: Ja, we're gonna go there. So I suggested we go to =coastal village's name= for a piece of fish and she enjoyed that. Came home. Ja. It was a pleasant weekend and she slept Saturday afternoon, which she never does. And she slept Sunday afternoon which she never does! During the day.

—

And... and I said it a number of times over the week. Actually last week already I was so pleased with her; that's why I said I will get you a DVD. (People talking in background in corridor.) And I only had the opportunity on Friday to get her another one. Because I was happy with her; I was pleased with her.

OC:

Mm.

Patricia:

So I thought: this is like a reward .

—

- Improved mood – enjoying outing to restaurant.

- Good parenting: Positive reinforcement of good behaviour.

Patricia:
For now that's how I feel because maybe it's because I had a good week with Sue.

OC:
Ja, it's linked.

Patricia:
I think that is why.

OC:
It's linked. So let's talk about that. Let's talk about that. Um, put it on the agenda. Anything else from your side? Have you managed to link up with =husband's name= a bit?

Patricia:
Mm. Ja, I did... We did talk about it, he knows... I said to him we must work together with Sue. If I said: "No, we're not gonna do this!" or "Let's not talk about it now!", he must work with me.

OC:
Mm.

Patricia:
And then I found, um, going through to =coastal village's name= yesterday afternoon, she was asking: "Are we going to stop at this? Are we going to Pick and Pay?" And we're always going to Pick & Pay in =suburbs name= near us on a Sunday evening. 'cause they're open till eight. We're going to Pick and Pay and we're gonna buy... And she was repeating what we're gonna buy.

- Attributing improved psychological well-being to child's behavioural improvement.
- Process: assertive towards husband; talking about her unhappiness w.r.t. his attitude and management decisions; husband changing – is this sustainable?

OC:
Mm.

Patricia:
So I said: "Yes, Sue." Uh, I'm agreeing, I'm saying: "Yes, that's right. It's quite right." And... then =husband's name= started. So I kept quiet. And then she said again: "Are we gonna buy cheese, and cheese, and cheese?" She repeats: "Milk and milk and Coke and Fanta and blue cheese for me and blue cheese for me and blue cheese for me". And this is exactly the way how she's saying it. And I'm quiet because I thought: this has been carrying on for too long now. I'm not gonna answer; I'm gonna get upset. I don't want to pick up, pick up bad vibes. So =husband's name= started: "Yes, Sue, that's right Sue." where I stopped. And I just looked at him.

Patricia:
Something I think I've changed. Yeah, because of what I learned here. I changed, you know? And I actually took a piece of paper and thought: what am I gonna write about? What am I gonna mention about Sue? And so far... That was Thursday.

OC:
Mm.

Patricia:
Nothing. (Inaudible segment) I thought: I'm not even gonna try and think of something...

OC:
Mm.

Patricia:

- Process: Reflecting on change and attributing it to therapy.

<p>... small. What's the point? Because there was no argument; raising voices.</p> <p>—</p> <p>OC: To becoming more. So every time she interacts in a pleasant manner, please reinforce her, please praise her.</p> <p>Patricia: [cross talk] Yes! Which I have been doing this week, I realise it does work.</p> <p>—</p> <p>Patricia: My dressing table she re-arranged to the way she wants it. Everything on the edge and in a row . I left it, I thought I'm not gonna... usually I'll say: "Put that..." or I'll just go: "Put it right!" I thought I'll leave it. It's not the way I want it. Up until the very last, last night, she went into the kitchen. She [inaudible segment], which she hasn't done before. [Inaudible segment] dish rack to the other side of the sink.</p> <p>—</p> <p>OC: And it's the (same) attention Sue will seek neg... the next time, maybe by also then engaging in a similar behaviour.</p> <p>Patricia: [cross talk] Ja. Like it... Ja. Like a two year old would. Mm.</p> <p>OC:</p>	<ul style="list-style-type: none"> • Whilst discussing autism, Patricia reflects on implementation of positive behavioural strategies – which she thinks is working. <p>Child's mental health: autism-related behaviour: obsessionality.</p>
--	---

<p>So, the plan is, Sue, if okay with you what we touched on last week during our last session is: If Sue... Should Sue's behaviour, you know, deteriorate again, um, it will be wonderful to start a positive programming approach with her.</p> <p>Patricia: Mm.</p> <p>OC: When she's good you praise her, when she's bad you ignore it.</p> <p>Patricia: Mm.</p> <p>OC: And it's almost like counterintuitive because, um, you want to do something a bit more firm in order for the behaviour to stop.</p> <p>Patricia: Mm.</p> <p>OC: But this is a low arousal approach.</p> <p>Patricia: Yes, yes.</p> <p>—</p> <p>Patricia: No, I'll tell him how to deal with her; the best way to deal with it, for us to deal with it now for the next week.</p>	<ul style="list-style-type: none"> • Process, agenda: discussing low arousal approach. Psychoeducation and skills training. <p>Coping through praying.</p>
--	---

<p>—</p> <p>Patricia: I mean... Everything can happen. I believe in prayer, and I've been praying for good behaviour in Sue.</p> <p>—</p> <p>OC: Mm. Is it linked, maybe, with worrying that something very bad will happen if you don't attend to it?</p> <p>Patricia: (Pause) I don't know where it's linked from. I think it's linked... I've got to do it. I have to do this and I have to be there.</p> <p>OC: Mm.</p> <p>Patricia: I think it's part of my nature, which I got to work on.</p> <p>OC: Mm.</p> <p>—</p> <p>Patricia: If... it could be like a compulsive behaviour as well, because...</p> <p>OC: It feels a bit like a compulsive behaviour, ja. I have to..? [cross talk] [inaudible segment]</p>	<ul style="list-style-type: none"> • Constant vigilance.
--	---

Patricia:
[cross talk] I have to do this - I have to check if the windows are closed.
And I say to him: "Did you do it?" If I'm in bed before him.

OC:
Mm.

Patricia:
Um, it's like... (Pause)

OC:
Mm.

Patricia:
It's not easy to... not do the worst things. No, it's not easy because if I
haven't done one of it... it bugs me.

—

OC:
Okay? The second part of this is, Sue, what is your feeling about
medication in general?

Patricia:
I don't want to... I wouldn't like to go on medication ...

OC:
Mm-hm?

Patricia:
Because I always never wanted to go on medication because my mother
was addicted to Valium.

- Compulsive behaviour – OCD traits?
- Maternal mental health: Describing generalised anxiety; events that are stressful and anxiety-provoking outside context of caregiving.

- Introducing possibility of referral for medication to treat depression and anxiety.
- C worried that she will become addicted.
- Psychoeducation followed.

OC:
You told me that, mm.

Patricia:
And I've got an addictive nature .

—
And to start changing my way of thinking a little bit and start doing things for myself. And what also lifted me up was Thursday, I went to go have a pedicure.

—
OC:
Did you think a bit more about that in the week that gone... that went by?

Patricia:
(Long pause) There wasn't much to think on that one. We did discuss it; about working together and him... the way he's keeping the peace.

—
Patricia: Thinking in my head: Okay, shut up now, I've heard it enough! I've been more calm inside. (Door slammed in background). Listening to her, but not zooming in on her and listening to everything. [inaudible segment] the curtains straight, pick up something, pull the table straight.

—
Patricia:

- Self-care- pedicure – improved mood. Behavioural activation = delayed but there.

Behavioural change – discussed management of Sue's behaviour with husband.

- Self-regulation – taking metacognitive stance.

<p>Even when... Well, not this past week, before I have been trying when she says something to me, I... (sighs) Actually, my daughter said to me: "Mommy, just look at the wall and think something . Don't get angry with her, because she sees it in your face."</p> <p>OC: Mm. Mm.</p> <p>Patricia: "Don't get angry with her, just look somewhere else and iffing and bitch if you want to, but say it in your mind!" I said to her: "=Other daughter's name=, do you do that?" She said to me: "Yes, I do."</p> <hr/> <p>Patricia: Even when... Well, not this past week, before I have been trying when she says something to me, I... (sighs) Actually, my daughter said to me: "Mommy, just look at the wall and think something . Don't get angry with her, because she sees it in your face."</p> <p>OC: Mm. Mm.</p> <p>Patricia: "Don't get angry with her, just look somewhere else and iffing and bitch if you want to, but say it in your mind!" I said to her: "=Other daughter's name=, do you do that?" She said to me: "Yes, I do."</p>	<ul style="list-style-type: none">• Coping through self-controlling.• Discussing non-verbal behaviour and Sue's picking up on subtle changes as part of autism.
---	--

<p>—</p> <p>Patricia: About the way I’m dealing with her. But just... ?(it’s not easy)? I’m not gonna say it’s easy. I’m not... I mean there’s other life issues...</p> <p>OC: Mm?</p> <p>Patricia: That I’ve got to deal with at the same time. I mean, it’s not a bed of roses: I’ve got the children with issues; I’ve got my husband; I’ve got myself. And Sue. So I try to deal with Sue in a more positive way and not looking at the bad side of everything. Like she’s... N-not looking at the fact that she’s going to perform; she’s going to break a window and she’s going to do this. At this stage, maybe because I had a good week, I’m thinking more positive and more relaxed with her.</p> <p>—</p> <p>Patricia: So she said: “Can I go and sleep for a little bit?” And I said: “Of course you can sleep!” I said: “Do you want me to come put a blanket over you?” She just said yes but call me when we go shopping. I said yes. Now I looked at the scenario, I said: “=Husband’s name=, we don’t have to be here, you know?” Sue is sleeping, =other daughter’s name= is sleeping, =son’s name= is busy washing the car. And his son, =grandson’s son’s name= is watching TV.</p> <p>—</p> <p>Patricia:</p>	<ul style="list-style-type: none"> • Starting to move away from Sue – discussing family conflict. • Engaging with husband w.r.t. behavioural management – behavioural change and skills aquisition. <p>Becoming more assertive towards other children.</p>
--	--

And this was about two 'o clock the afternoon. So I said to =son's name=: "When =other daughter's name= wakes up, tell her we gone out for an hour or two? You can phone us." And we did that. We went to =husband's name's= brother, we went to go have a burger. And we went to my sister, and we went home.

OC:

Good for you, Sue.

Patricia:

And it was... =Other daughter's name= was *dikbek* (sullen). You know? Like how could you? But I realised we should've asked her.

—

Patricia:

I've been through it with my so-, with =son's name= before. Uhm, he was sleeping there on weekends. And they... We live in =suburbs name= and the live in =another suburbs name=. I said: "But you don't have to be here on weekends." If there wasn't a spare bedroom they'll take a mattress and sleep in the lounge! This is before they had the baby!

—

Patricia:

And it took a lot of time before I could sit down and tell them. Because I'm not so, I don't want to be upfront like that. And they were in my room. I got home one Saturday afternoon and they were laying in my room watching TV. I said: "Look: I don't want you guys sleeping here anymore." And I just explained to them.

OC:

- Parental stress due to behaviour and interaction with other children.

- Family tension.
- Enmeshed family
- Process: Start of discussion of family dynamics and especially the enmeshed nature of family interaction and time spent together

- Family conflict.
- Feeling used and unappreciated by other children.
- Other children not allowing her enough space.
- Increased assertiveness towards other children.

[cross talk] (inaudible segment)

Patricia:

“But why?” I said because I need my space. “Yeah, but we’re not in your room! We’re always sleeping in the lounge.” I said: “Yes, but when I get up on a Saturday morning or a Sunday morning, I want to go and sit in my lounge.”

OC:

Mm. Mm.

Patricia:

But I don’t want to go back and sit in my room.

—

Patricia:

There’s more than likely milk she’ll ask for. Then I tell her: “You can wait till the morning.” And I say to him. Then he says: “Ag, shame.” Then he’ll phone maybe =son’s name=. =Son’s name= lives in the same block of flats. “Don’t you want to go buy your sister some cigarettes?” (Laughs) Milk or whatever. He’s always trying to please them. If he can’t do it, then many times I stop him completely. So now you’re not gonna do it, it’s not necessary.

OC:

Mm.

Patricia:

She can wait till the morning or she doesn’t need the milk. She more than likely wants the cigarettes

—

- Dissatisfaction about relationship with daughter.
- Family stressors and parental stress.
- Daughter using them to obtain items and food.

OC:
And let's work on it a bit and see if we could make a bit of headway? I think we need to keep on going with that, if that's all right?

Patricia:
Ja, we could that. Mm.

OC:
Okayay.

Patricia:
And the story with the pictures. With all the photos, there are a lot of photos!

OC:
Yes!

Patricia:
But I haven't... I'm not sure now... With all the photos... (Sighs) I mean it's people that visit us and people that we visit. It's their children. So it's a lot. So I haven't put it on anything. I'm not sure must I put everybody's on one? No.

OC:
Every single photo should be separated.

Session 9

Patricia:
It wasn't every day that was bad... it was the constant, uhm... (Long period of silence) repeating that was hectic. But we try to work to-together, but...

Process: Homework. – get pictures of families to use when obsession of Sue starts
– who is coming to visit? Patricia appeared less motivated to do this.

- Parental stress due to child's behaviour – repeating and obsessionalities.

We spoke about it... =husband's name= and I and the kids. Uhm, (sighs) just to try and... If she ?(asks)? to a standstill and listen, just to do it.

—

Patricia:
And we both agreed on just thinking... on just thinking on something else, but try and not let her see that we're not really listening but we are there .

—

Patricia:
She wasn't in a good space this week. The week before she was nice... She stopped listening to =boy band's name=...

OC:
I remember, yes.

Patricia:
She asked me again to put it on for this week.

—

Patricia:
Coming home from work, "I'm not going." Deciding she's not going to go to work and then =husband's name= convincing her: "Okay, I'll fetch you early." Uhm... Ja. Saturday morning was hectic. Six o'clock the morning she came into the room. "What we're doing today ? Tell me what we're doing?" and she found a little album that me daugh... that my son's girlfriend gave me for my birthday with photos of their child from birth up till six years. And she's looking at it; sitting on the bed looking. She says: "Can I cut out the picture?" You know, this but I said: "No, but I'll get you

- Working together with husband.
- Coping through problem-solving.

- Parental stress due to child's behaviour - obsessions

- Having to be on guard 24/7: constant vigilance.
- Child's behaviour: Physical aggression directed towards mother.
- Demanding behaviour.
- Helplessness.

the picture. =Son's partner's name= gave that for my birthday, you can't cut pictures. I'll get you a picture." "But I want this one." I said: "Sue, you can't." And she picked up, I've got a candle standing, she picked up that and she threw... I wasn't around the bed yet, she threw that at me and she threw the cup and... Because she wanted this picture. So I said: "No, (inaudible

—
Patricia: Miserable... Last night, played music right through the night. Didn't want to get up and ask her because it's gonna be a whole long story again and "I'm not going to work tomorrow" and da da da da da. So I thought I'll just left it. Didn't sleep much and thought, just prays she goes to work this morning. You know, there's a whole big scene this morning. I was pleasant, I said: "Hi, Sue!" When I got up she was sitting in the lounge. I said: "Ooh, it's a beautiful day today." And I made myself chirpy.

—
Patricia: ...I was scared and crying (tremor in voice discernible). But it was a horrible, horrible experience which didn't happen for a long time.

—
Patricia: She's just on this thing about now coming home early. And I actually must try find to see if there's anybody upsetting her at work or the reason why she doesn't want to be; that's what I'm planning to do now when I go home.

—
Patricia. Uhm, the seizures, I would also still say it was once or two a night. I didn't hear anymore or didn't see anymore and it is only at night. Nothing's changed there. Ja, but other than that we are trying to... I am trying to deal with it the best possible way. Trying to think positive...

- Keeping a "chirpy" face – daughter scrutinises facial expression – feeling sad and stressed but not able to show it.
- Coping through problem-solving.
- Child's physical health: seizure frequency remained the same but behaviour deteriorated.

—
Patricia:

Uhm... Ja. So he's saying to her: "Okay, =daughter's name =, I will!" But she knows he's not gonna come at lunch and she knows... She's not that stupid. But she's not stupid at all. She knows he's gonna come later. But what he does do is fetch her earlier than usual. If it's not gonna be lunch time he'll fetch her earlier.

—
Patricia:

And when she's busy there, she's been... They haven't complained; I haven't got complaints yet for a while from =workshop's name=. I used to have lots of complaints about Sue. But for a good few months I've had no complaints.

—
Patricia:

And he did see that there's... We can't reason with her, there's no reasoning. We can get Sue going by saying something to her. If she was sitting here I could say to you: "You know, Sue... (long pause) doesn't want to stop drinking Coke and it's not good for her." And she'll be gone, she'll cause a big scene here: "Say I can drink Coke, say I can drink Coke!" And then she'll start turning something on the desk because you're not saying 'yes'.

OC:

Ja.

Patricia:

So we can push her, pu-, but we're always trying to keep her calm.

- Dysfunctional parenting: Husband telling lie to keep the peace.
- Daughter's behaviour better at work than home (considerably)
- Arousal levels too high to employ confrontive coping or be assertive w.r.t. behavioural change..

<p>—</p> <p>Patricia: =Husband's name= stayed home and I went out. It was all right, but after what happened the morning I was still, I wasn't feeling good about myself, or anything.</p> <p>—</p> <p>Patricia: Feeling down. But I went out Saturday night. Ja. Otherwise that was all.</p> <p>—</p> <p>OC: How did you understand that? I mean, I was also disappointed because I was hoping that one could actually do something. That the psychiatrist could actually do something about the... What did you understand..?</p> <p>Patricia: [cross talk] No, he just mentioned... No, he just mentioned the fact that Sue will more, probably go... She'll probably go for more psychology...</p> <p>OC: Did he..? Did he describe and explain to you why he didn't prescribe anything?</p> <p>Patricia: Mm-mm. No, he just... He did explain the fact that she's on her medication and it's gonna counteract, it could counteract way against her... How did he explain it now?</p> <p>Patricia: If she's gonna take medication now, it's gonna cause problems with the</p>	<ul style="list-style-type: none"> • Depressive symptoms – continues to read but lack of enjoyment. • Depressive symptoms • Daughter visited psychiatrist as part of MDT intervention. • Epilepsy dictates caution w.r.t. prescriptions – made Patricia feel helpless even though she understood where psychiatrist was coming from.
---	--

seizures. It could cause problems with the seizures.

OC:
Lower her seizure-threshold?

Patricia:
Yeah. Yeah.

OC:
Yeah.

Patricia:
So I understood that. And I just thought when I got home... I didn't think then I was going to have asked him could he give her Valiums or something for bad days? Or sleeping tablets so she could have a good night's sleep?

—

Patricia:
So I see the fingerprints on the TV and the little ones haven't been by the TV, so... it's definitely, and it's high up where they can't reach!

OC:
Mm.

Patricia:
So she's definitely touching the TV again and touching... but she wasn't doing that often. And, uhm... There has been talking. She hasn't seen people or hear things.

OC:
Ja.

- Child's behaviour and mental health – psychotic, P implying that she is ?more psychotic – behaviour worse. Tentative link (other variables to consider and internal sense of unhappiness?)

Patricia:

She doesn't, she (inaudible segment). It has got a lot to do with the TV: they're talking to her and sometimes she gets angry (when) they pull a face. They're pulling faces at her .

Patricia:

He's not saying much, but he's... like he's more understanding with her, more patient. Before he used to say: "Agh, I told you already now leave me alone!" He's always wanted to be short, but... short-tempered.

Patricia:

But it's not nice, I don't want to. But only on my bad days. On her bad days, when I'm feeling crap and I don't want to cope anymore; I don't want this anymore, I feel like giving her that. And I understand why they did it. You know? But I don't want to, because there is better days. There are some better days like she went to work this morning, so it's a better day for me.

Patricia:

First we had the crap but she went so therefore it is a better day. So, ja it's crap! But I have to just deal with it and I can't see myself... I have to think about it, you know? Blocking her out. Let her go sleep. I think about it but I have to think about the consequences. When she wakes up she's gonna be irritable because of the tablet I've given her, maybe.

OC:

- Positive family support – son described as more patient.

- Parental stress and mood described as following Sue's behaviour.
- Depressive symptoms.

- Trying different coping strategies to deal with child's behaviour: avoidance, problem-solving, accepting responsibilities.
- Starting to reflect on earlier caregiving experiences.
- Formative influences: Sue placed in group home –
- Process: Looking at longer standing issues during latter part of therapy.

Yes. It's not only the tablets that gave her that veggie type of state.
=Residential care facility's name= is not a group home, it's a residential care facility.

Patricia:

[cross talk] They don't do very much, (inaudible segment). They're not motivated, there's nothing happening there.

—

Patricia:

You know (inaudible segment) and I know my other kids won't look after her. They say they will but they can't, they haven't spent enough time with her, even today while we're there. I couldn't believe that they'll look after her.

—

Patricia:

(Long pause) I'm just please that's she's there; I'm just very pleased that she's happy at =workshop's name=. And good and quiet and peaceful, because it was hell when they wanted to put her out there. It was terrible.

OC:

I can imagine.

Patricia:

I was scared for that phone call: "Come and fetch Sue". She's had a couple of scenes there where we had to go and fetch her, because she arguing and fighting and because ?(maybe)? one or two of the friends would say something to her that she didn't like.

—

- Lack of family support (from other children): Other children not assisting with caregiving - conflicting.

- Apprehensive expectation about placing Sue at workshop – worry that her behaviour will cause expulsion.

OC:
I just wanted to make sure about that one, Sue, because I mean: I'm-I'm really... Sjoie, the fact that Sue is doing better at =workshop's name= is most likely is because she relates to you in a different way; that she relates to her own people, her family. You see it with kids all the time.

Patricia:
Mm.

OC:
And that's the problem.

Patricia:
[cross talk] But (that's) always the case, always the case! They know who they can mess around with!

OC:
Mm, it's family...

—

OC:
Uhm, okay. So I'm just trying to construe this in a slightly different way. Do you think it will be useful to apply (for placement) to a place like =group home's name=? for placement for Sue?

Patricia:
I wouldn't think it's useful because they're not gonna put up with =daughter's name = 's crap!

OC:
Okay! But will her crap be as pronounced in a place like =group home's

name=?

Patricia:

(Long pause) (Sighs) I don't know... Well, it was happening at =group home's name =.

—

Patricia:

Mm. Ja.

OC:

I'll definitely link up with her as well. And just to-to probe a bit as to how things currently are with =group home's name= specifically.

Patricia:

Mm. Okay.

OC:

If she wants to [cross talk] (inaudible segment)

Patricia:

=Other group home's name=? =Other group home's name= is where their workshop is.

OC:

Yes. =Other group home's name= is also an option. I just think that the =group home's name's match between =housemother's name= and Sue will be especially advantageous.

—

Patricia:

- Negative attitude towards child.
- Process: starting to look at future of mother and child – group home placement.
- Lack of social support (formal) – no group homes to manage Sue's behavioural difficulties.
- Exclusion due to behavioural difficulties of child.

- Process: problem-solving possible placements for Sue and where to apply
- Discussing different group homes (part of longer excerpt.)

<p>[cross talk] Investigate, ja. [cross talk] (Inaudible segment) I could do it, ja. Ja, I need to do that .</p> <p>OC: To link up with =social worker=. Apart from those group homes, uhm, there's a group home in-in =town's name= called =group home's name= that... It's a small group home and it's a bit far, though?</p> <p>—</p> <p>Patricia: [cross talk] Mm.</p> <p>OC: It's almost a bit like isolation, I don't know .</p> <p>Patricia: Mm.</p> <p>OC: =Another intentional community's name= is the other option.</p> <p>Patricia: Ja, we've tried =the intentional community's name=... But they're also a bit pricey.</p> <p>—</p> <p>Patricia: It is a bit better because he does realise we've got to work together . It's no good with me saying yes and him saying no or either way.</p> <p>—</p>	<ul style="list-style-type: none"> • Outcome – investigate group home options with social worker <p>Discussion and problem-solving about way forward with regard to future placement .</p> <p>Developmental pathway and transition of parent and child – old age and midlife.</p> <ul style="list-style-type: none"> • Management of child's behaviour – communication and assertiveness towards husband improved.
--	--

Patricia:
Ja, nothing, eh... It was okay... because we're working together and we can talk more to each other although sometimes we're both just *gatvol* (fed-up), we don't want to talk about it.

OC:
Mm.

Patricia:
But... Ja! No, it's much better.

OC:
Much better. Okay. And...

Patricia:
[cross talk] I realised I can't take my anger out on him.

Patricia:
Ja, nothing, eh... It was okay... because we're working together and we can talk more to each other although sometimes we're both just *gatvol* (fed-up), we don't want to talk about it.

OC:
Mm.

Patricia:
But... Ja! No, it's much better.

OC:
Much better. Okay. And...

- Relationship towards husband improved.
- Anger towards husband lessened.

- Managing Sue's behaviour – employing wider variety of coping strategies.
- Thinking critically about behaviour and trying different things out.

<p>Patricia: [cross talk] I realised I can't take my anger out on him.</p> <p>—</p> <p>Patricia: Hit it off. Okay! Okay, I didn't think of that!</p> <p>OC: [cross talk] Take your arm and...</p> <p>Patricia: We always try and pull away</p> <p>—</p> <p>Patricia: Mm. Started seeing her being drugged and I wasn't happy with...</p> <p>OC: I can imagine!</p> <p>Patricia: So, she was happy because she was in a group home. I was happy, because we weren't seeing her every weekend. She came home every second weekend. We ?(spoilt)? her and we did the wrong things, because we were under the influence.</p> <p>OC: Mm.</p> <p>Patricia: And we were always: "Shame, poor Sue!"</p>	<p>Parental skills training – showing Patricia some of the techniques to prevent injury and manage crisis.</p> <p>Earlier experience of placing Sue in group home. Maternal mental health – substance dependence. Feeling guilty about Sue's placement and overcompensating during weekend visits by giving her her way in all or most of her requests.</p>
---	---

OC:
Yeah.

Patricia:
You know? She's not at home every day like other children, give her, her own way!

OC:
It's very normal, isn't it? To...

Patricia:
[cross talk] But even those days it wasn't like one or two or everything when she went back on a Sunday night. Most-... it was mostly every weekend.

OC:
Mm.

Patricia:
It was always like four, five, six milkshakes and... we did it.

OC:
Mm.

Patricia:
We did it because we were happy she was going back to...

OC:
Ja.

Patricia:
=group home's name=.

OC:
Ja, ja.

Patricia:
So we spoilt her. Because everything was... those days of the autism side, we didn't know. I can see it now ?(with)? the display and the soaps and everything was also lined up; doubled off everything.

OC:
Ja.

Patricia:
The shampoo went down; she topped it up with water.

OC:
Yes, that sounds very much like it.

Patricia:
Yes. Those days already and this is like eight, ten, fifteen years ago. And I remember all these things. But ja... We're not gonna get rid of the problem.

—
OC: sound of pen on paper, writing something down) Behaviour. (Long pause) (Voices of people talking in corridor in background). And your behaviour. Okay, so for-for next week, if it's okay with you, Patricia, can we get a fifth column going?

Session 10

Patricia: Nothing different. Uhm, there was no big outburst .

- Time ran out – could not attend homework assignment – homework assignment given – continuation of 5 column DTR.

OC:
Uh-huh?

Patricia:
I think that I was... I was a bit, uhm, for example, getting ready to go to church yesterday morning she decided, no, she's not going anymore.

—

Patricia:
Uhm, nothing big happened this week, just the same, the repeating and especially when... Don't know what's happening in her head that she'll say to me: "Say 'friends!'"

—

Patricia: Yes, she can't function otherwise; like she can't go forward with what she was busy doing!

—

Patricia: And never mind... Sometimes I got to shout the words: "Say it again! I can't hear you! I can't hear you!" And I think now: is this for real or is she acting? But I realise that something's not happening there; that's she's not focusing. But how many times we say it!

—

Patricia: That happened once. Now that I'm thinking about it, it happened once in December when it was so bad that she pushed the fridge over. Well, not over she moved the fridge to the other side of the kitchen and it was terrible! Terrible, terrible, terrible that she scratched there, she bit

- Lack of behavioural outbursts: child.
- Child's behavioural problems: autism-related problem behaviour.
- Showing insight into her child's problem behaviour.
- Child's behaviour: autism-related obsessions, repetitive speech and listing contributing to parental stress
- Recalling incident that described severity of consequences should family refuse to repeat sentences = selective abstraction? (without trying to lessen valid experience of having to deal with difficult-to-manage

<p>herself, she... And all because =son's name= said: "I already said so, I'm not saying it again."</p> <p>—</p> <p>Patricia: I mentioned it to her. She said I must fill in the forms, and she explained to me how their system works.</p> <p>—</p> <p>Patricia: I think I am. (Voices of people talking in background discernible) Maybe because nothing happened. Like you know, she didn't, wasn't no big scenes.</p> <p>—</p> <p>Patricia: Ja, I'm feeling down, I'm... (long pause) I haven't... I'm not at the depressed side; I'm not that depressed. I won't say I am. Maybe I am and maybe I'm in denial. I don't know.</p> <p>OC: Mm.</p> <p>Patricia: I'm not that depressed that I want to curl up in the bed and go sleep. I do think about it, you know? Just throw the blanket over my head and... But not that bad.</p>	<p>behaviours.)</p> <ul style="list-style-type: none"> • Coping by problem-solving: Made contact with social worker to apply for group home placement later on . Followed-up on our discussion from previous session. • Attribution of globality? Improved psychological well-being attributed to absence of behavioural difficulties during the last week. • Mood objectively observed as depressed. • Met symptoms of depression in last sessions. • P finding it difficult to rate mood. • Description of what depression might be like describes severe depression.
--	---

<p>OC: Ja.</p> <p>Patricia: Not that bad.</p> <p>OC: It-it... We started with about ninety, and then it went down to... consistently to about sixty.</p> <p>Patricia: Mm.</p> <p>OC: It's still there?</p> <p>Patricia: Yes, yes, definitely. It's not good at all.</p> <p>—</p> <p>Patricia: Yes, yes, he helped me with...uhm, my alcoholism. I went to him when I looked like a... a drowned rat then I went into his office.</p> <p>—</p> <p>Patricia: And uhm, on the fifth day I thought: Okay, the Valiums (voices heard in background from office next door) The Valium had worked, there's no more Valiums. I went back. So with the last Valiums the shakes started coming back.</p>	<ul style="list-style-type: none"> • Cognitive distortion: discarding the positive. • Maternal mental health: previous alcoholism. • First time in therapy, talking openly about alcoholism - ?formative influence.
--	--

OC:
Mm.

Patricia:
And when I went back I thought, you know: I might need to take the Valium to get rid of the shakes because I don't want to drink anymore. And I know if I had a drink, it's also gonna get rid of the shakes! Because I was like trembling head to toe. People used to ask me if I'm cold.

—

Of therapy or whatever... (voices in background discernible) I can do not to drink, because I don't want to drink anymore. And, uhm, that was my first admittance that I was an alcoholic. And then he introduced me to AA and I never needed medication. From then, I've been, uhm, I had a scene ?(once)? with my son, he lost the plot, he was on drugs and he says he wants to wipe us out.

OC:
=son's name=?

Patricia:
Ja.

OC:
Okay.

Patricia:
And, uh, I went back to him again. And he put me on a course of... Not a..., well, he gave me a few antidepressants because I was besides myself! We weren't even in the home. We hid away from =son's name=.

OC:

- Spontaneously describing earlier painful and traumatic events.
 - Parental stress – earlier – and trauma because of another child.
-
- Earlier trauma and parental stress caused by child who does not have ID.

Patricia:
Because if we didn't hide from him, we would've had him locked up,
because I had a... I took an interdict out, because we were very scared and
he had a gun. (Voices heard in background) Because he was losing it, and
went into the drugs.

OC:
Ja?

OC:
Mm.

OC:
Mm.

- Maternal mental health – GAD .
- Attributing onset of substance dependence with daughter's epilepsy and caregiving stress.

749

With Sue having seizures one after another. I felt like I became a nervous wreck. I don't know if I'm talking crap but that's what I...

[cross talk] No, no, you're not talking crap at all!

[cross talk] That's why I was a nervous wreck all the time. Coping with Sue, basically =husband's name= was there but he wasn't there. Basically on my own. I would say.

Mm.

And I... the amount of seizures she used to have!

No, no, no! The world moved on from-from those medications. They
 ?(made those)? in the sixties, you have better stuff available these days.
 Patricia, my sense is that this is really fundamental and we need to maybe
 spend a bit of time on that.

Mm.

I will love to explore that with you. (Turning page) Hopefully we'll have

- Cognitive distortion – overgeneralisation.
- Lack of family support from husband when Sue was young.
- Helpless – core belief – I am helpless. There is nothing that I could do to help my child.

- Agenda item – discussing possibility of referral to doctor for treatment of depression.

enough time going through this, but it's very much connected. Uhm, I'll try to show you in which way.

—
Patricia: I'm just thinking: How did I cope with that child? I really felt like I was going insane myself because, like I said, when it wasn't a fit happening, after ?(every)? day, like I said there was some days she had a hell of a lot, one after another.

—
Patricia:
And she wakes up and have another one, and goes off again and have another one! It was scary, for me it was very scary! But I managed to be there all the time for her! Continuously. Even when she was in hospital I stayed with her. With every hospital visit, or should I say every hospital stay, I was with her all the time! I did my best as a parent,;that I do know! I can say so today.

—
[cross talk] Yes. So we spoilt her, everybody spoilt her, and we are sorry today!

OC:
Yes.

Patricia:
She was spoilt by everybody.

OC:
If you didn't spoil her, do you think she would've presented dramatically

- Process: discussing thoughts that might have developed when Sue was young – formative influences.

- Formative parental influences: Core belief – I am scared what could happen to my child. Parenting is scary. I am not in control

- Formative influences on parent-child interaction: spoiling her and giving her way.

different?

Patricia:

I'll say today if she wasn't spoilt, she wouldn't want her own way all the time! I think to myself, I believe that she's spoilt, so that's why she must have her own way. But now it could be the autism, it's made me... I'm beginning to understand it now. That's why I'm looking at Sue in a different light, because I realise there's something else wrong. The doctors always put it down to mild retardation. And severe epilepsy. That was Sue's diagnosis. Sadly enough.

—

OC: And going right back and saying: what are your thoughts going with this? Why... what are your thoughts about Sue's behaviour present when it relates to the way you raised her? What's going through your mind?

Patricia:

A lot goes through, I just thought maybe she was... she is spoilt; the way we raised her was by giving her, her own way; feeling sorry for her. Every seizure I felt I had to be by her side.

OC:

Mm. Mm. Mm. Mm.

Patricia:

?(Watched)? each one. See that she was okay with each one.

OC:

Mm.

Patricia:

So no matter what I was doing I would feel that wherever she was playing,

- Formative parental influences – beliefs about earlier experiences covered.
- Events – had to constantly monitor her in case she had seizure: constant vigilance.
- Felt sorry for her – guilt? – overcompensating.

<p>I would be there by her side.</p> <p>OC: Mm.</p> <p>Patricia: It was draining, it was mentally draining for me. And like I said, ja, I felt like I was gonna end up at =psychiatric hospital's name=. I was gonna lose the plot!</p> <p>—</p> <p>Patricia: Ja! I would rank it not too high because today I realise it's not...</p> <p>OC: No, but you're going too far! (Laughs) You're going too far!</p> <p>Patricia: When I rank it then, extremely disappointed because, ja: my fault! I did blame myself and I blamed =husband's name= because he wasn't there to help me.</p> <p>OC: Yes.</p> <p>Patricia: Ja.</p> <p>OC: Okay, so what was going through your mind maybe is, in years gone by, is: I am to blame!</p>	<ul style="list-style-type: none"> • Present belief: Child is having difficult to manage behaviour because she is spoilt – attribution of intentionality and controllability. • Core belief: I am to blame (intermediate belief in the context of caregiving – I am to blame for her behaviour because I spoilt her).
--	---

Ja! Because not knowing when is it gonna happen again, when is it gonna happen again? It's like an alcohol, uh, uhm... wife of an alcoholic or husband of an alcoholic waiting for that person to come home blind drunk.

Patricia: Like if I had the whole morning, then fine! But I still had to do some stuff for Peter and I thought I don't have time to stand here and explain all this.

OC: Mm.

Patricia: And I walked away, thinking, you know, whatever.

OC: Bear with me now: when that was happening, what was going through your mind this time?

Patricia: *J**** Ch****, not again!*

OC: Okay. Now, go back to the seizures and when she was a baby and having those seizures. What was going through your mind at the time?

Patricia: [pause] The same thing!

OC: Okay, so why . . . ?

Patricia: [cross talk] Not as bad, not as . . . it was worse then.

OC: Of course it was worse!

Patricia: It was worse then!

OC: *But J****, not again!* When she was having a seizure, what was [sic] your fear(s)?

- Connecting formative influences with present evaluations of threat that lead to parental stress.

Patricia: I was fearful, scared that she's gonna hurt herself.

OC: Or die?

Patricia: Yes! Yes! I always thought the worst.

OC: Okay.

Patricia: I always thought the worst is gonna happen to her.

OC: (speaking softly) As if it isn't terrible enough to . . .

Patricia: Hm. We always used to ask the doctor, can, you know, what can happen to her? And all he used to say to us were: "*See that she can't hurt herself.*" (Sighs) Ja!

—

Patricia: I'm just a nervous person from the word go.

OC: Mm. Mm.

Patricia: And now... ja.

OC: It's been like that your whole life?

Patricia: All my life.

OC: Yeah?

Patricia: All my life. I was a nervous wreck before I even got married because of my upbringing. So it stayed with me.

- Formative influence – childhood – strict, verbally and authoritarian father and mother dependent on substance-use.
- Anxiety and stress now linked with events other than caregiving.
- Maternal mental health: Generalised anxiety.

OC: A very strict father?

Patricia: Ohhh! Hitler. OC:

OC: No matter what you did nothing was good enough? (Pause) Was he aggressive?

Patricia:
Oh, with his mouth. Verbally abusing.

OC:
Ja.

Patricia:
But...

OC:
[cross talk] But he also drink a bit too?

Patricia:
Oh, yes. A bit too much.

OC:
And mom. Was she absent?

Patricia:
She was absent because she... was on a Valium trip. She was there; she was a good mother... She thought she was a good mother, because she had seven children and she stuck at all the... Those days it was different.

OC:
Oh no, yes!

Patricia:
I was on my nerves. So I was... I went to the shop and I'll never forget there was a time, I was young, maybe five or six, and I had to buy a jar of peanut butter... at the bubby shop around the corner. And I dropped it.

OC:
Mm. Oh!

Patricia:
And I came home with the broken jar in my hand and I said they gave it to me like that.

OC:
Mm.

Patricia:
That's how scared I was. I lied.

OC:
Ja.

Patricia:
So ja, we were... I was fearful. I was very fearful of my father. You know I never... You know when he died... I was eighteen years old when he died... and I think just a tear ran down my face. And I ?(just said)? thank you, God!

OC:
Ja. (Inaudible segment)

Patricia:
That's sad, and I felt guilty about that. I felt very, very guilty about that

- Formative influence – father's behaviour was unpredictable.
- Feelings of guilt – thoughts about father.

because I thought: This is my father! And I was brought up to respect your mother and father.

—

OC:
They withdraw and...

Patricia:
[cross talk] There we go! Ja!

OC:
They keep a very low profile as to survive. Many of these children then grow up and actually, sometimes revert back to the idea of: if I'm keeping myself below the radar, I'll be safe.

Patricia:
Mm!

OC:
Okay?

Patricia:
Mm.

OC:
There's a... There's a very deep (inaudible segment), and I can see it is resonating with you quite centrally now, uhm, Sue. So then you got a child who, every time she started screaming you thought she might die at any moment. Uhm, and you had to be there continuously all the time, every single day. Well, that's a baddie [sic]. (Long pause). Please, by all means cry. I have tissues galore for you. There we go!

- Non-assertiveness to deal with unpredictability as formative influence.

<p>Patricia: Ja, I don't know why that upset me now!</p> <p>OC: It's hitting home because it's an awful thing. (Long pause)</p> <p>Patricia: I mean, I always knew... I-we always used to talk about our childhood.</p> <p>OC: Mm.</p> <p>Patricia: Between my sister and myself, I always said: No, I don't want to talk about it. It's mommy, it's daddy, you must have respect for them. You know? But, uhm, ja, it was a raw deal and I'm.. I did try with Sue, I wanted to be there for her.</p> <p>OC: Ja.</p> <p>Patricia: At all times, like I said, even if she was in hospital I was there at her side. I stayed at the hospital, which, those days, they didn't mind, because it was a help for them. I was with her, by her side... (starts crying).</p> <p>—</p> <p>Patricia: Between my sister and myself, I always said: No, I don't want to talk about it. It's mommy, it's daddy, you must have respect for them. You know? But, uhm, ja, it was a raw deal and I'm.. I did try with Sue, I wanted to be there for her.</p>	
--	--

OC:
Ja.

Patricia:
At all times, like I said, even if she was in hospital I was there at her side. I stayed at the hospital, which, those days, they didn't mind, because it was a help for them. I was with her, by her side... (starts crying).

OC:
Mm.

Patricia:
And, uhm... Ja! (Pause) That's why I couldn't come to terms with the time when she was... Her last episode at hospital was also about eight years ago. (Pause) (Sighs) She developed pneumonia and they wouldn't have let me stay. It was the first time they told me I couldn't stay in the hospital with her.

OC:
?(Where was that)?

Patricia:
At =hospital's name=. That was the worst because I refused to leave... I said I'm not leaving. I was sober, I wasn't drinking anymore and I said: I'm not leaving, because she has the oxygen on, she's gonna pull it off. I said if she had a fit, the oxygen is gonna be off, and who's gonna be watching her?

Patricia:
No, they will check up with; they will check up on her. And that was Friday night. We went home. I phoned ten o'clock at night to see if she was okay... if the oxygen was on. I still said to the sister: please check if the

- Recalling significant life event as formative influence – daughter's pneumonia – not there, not constantly vigilant – daughter almost died.

oxygen's on because I know she's gonna have a fit, and that's gonna be off. And also Sue wouldn't keep the thing on...

OC:
Mm.

Patricia:
... herself. Every time she was pulling the thing off. (Sniffs) And that was my point, for her to stay and... For me to stay and at six o'clock the next morning they phoned again and uh, there was a doctor busy with her. I must come up immediately. She... her lungs collapsed. And when I got there they were busy pulling the pipe down. So that was like the scary part; that was like, I was always there. You know, even... Ja, that was when she came... The other time it was hard for me to ?(like)? be there? And Sue... (cross talk)

OC:
(cross talk) [inaudible segment]

Patricia:
Sorry?

OC:
?(Ward eight)? (inaudible segment)

Patricia:
Ja, it's not... little things that's upsetting me when she's not around, but I'm tired of it now.

—

Patricia:
... herself. Every time she was pulling the thing off. (Sniffs) And that was

- Formative caregiving event: I am vulnerable (and my child is vulnerable).
- I have to be on guard otherwise something bad will happen to my child.

my point, for her to stay and... For me to stay and at six o'clock the next morning they phoned again and uh, there was a doctor busy with her. I must come up immediately. She... her lungs collapsed. And when I got there they were busy pulling the pipe down. So that was like the scary part; that was like, I was always there. You know, even... Ja, that was when she came... The other time it was hard for me to ?(like)? be there? And Sue... (cross talk)

—

Patricia:

Like I can't go to bed, or should I say I can't go to sleep... (long pause) Still today, I'm not sure if Sue is sitting in the lounge or if she's in her room.

OC:

Mm?

Patricia:

It's like part of me has to, you know, have to do these things; it's part of being a mother. Meantime, I do realise I can just switch off and leave her. But things I have to do, and I'm tired off it.

—

OC:

Bear with me now: when that was happening, what was going through your mind this time?

Patricia:

J**** C*****, not again!

OC:

- Caregiving through the decades: Pile-up of caregiving stressors; accumulation.

Okay. Now, go back to the seizures and when she was a baby and having the seizures. What was going through you mind at the time?

Patricia:
[pause] The same thing!

OC:
Okay, so why..?

Patricia:
[cross talk] Not as bad, not as... it was worse then.

OC:
Of course it was worse.

Patricia:
It was worse then.

OC:
But J****, not again! But J****, not again! when she having a seizure, what was you fear?

Patricia:
I was fearful, scared that she's gonna hurt herself.

OC:
Or die?

Patricia:
Yes! Yes! I always thought the worst.

OC:
Okay.

- Process and identifying and modifying beliefs w.r.t. parenting and catastrophic automatic thoughts that were formed in early parental experiences.
- Core belief: I am in danger.
- Core belief: I have to be vigilant.
- Role of child's physical ill health on parental beliefs.
- Role of child's physical ill health on maternal perceptions w.r.t. child's behavioural difficulties.

Patricia:
I always thought the worst is gonna happen to her.

OC:
(speaking softly) As if it isn't terrible enough to...

Patricia:
Hm. We always used to ask the doctor, can, you know, what can happen to her? And all he used to say to us were: see that she can't hurt herself.
(Sighs) Ja!

OC:
Can you... Do you have any idea of how strong the belief system developed, because of the intensity of your emotions as a young mom? Jesus, not again! She's gonna die! Or hurt herself badly.

Patricia:
Mm! Mm.

OC:
That's, those are the thoughts, okay? And it led to very intense emotions. A couple of them.

Patricia:
Mm.

OC:
Maybe you kept some of those thoughts, because today when she looks as if she might become aggressive, what's going through your mind?

Patricia:
Hmm... The same thing, J****, here ?(there)? we go again.

OC:
[cross talk] Here we go again, because she's going to..?

Patricia:
Either that she's going to go ballistic, she's going to hurt one of us; I get scared, I get scared...

OC:
[cross talk] How bad is she going...

Patricia:
[cross talk] Like you said before: How bad is she gonna hurt me? Maybe throw me with something that might not even hit me!

OC:
It's a similar situation but I think you carry those thoughts from-from long ago...

Patricia:
[cross talk] I did. I think I did.

OC:
...to the present...

Patricia:
Yes.

OC:
And the question is: are they still as valid as they used to be? Because when she was a child..,

Patricia:

Hmm.

OC:

...there was every possibility that she would've gone into status epilepticus.

Patricia:

Yes, but she wasn't violent then.

OC:

No. It's about life and death, not about violence.

Patricia:

Mm. Ja.

OC:

(Long pause) So...

Patricia:

[cross talk] And that shifted a hell of a lot.

—

Patricia:

It feels like it at the time! That's how it feels at the time, but with the last episode, which was last Saturday on my bed, I handled it better. I was upset. I mean I didn't... I say I handled it better, but it wasn't better as such. It was a little bit better. It wasn't that... I freaked out; I was upset for the day, but there's times when these things happen when I was completely freaked out and I couldn't cope and I sat there and I cried, and I was teary during that day! I was upset during the day. I wasn't besides myself. So it is a bit better. I realised now, lately, that... how, or how bad can she hurt me? Or herself?

- Engaged in coping.
- Perceptions of limited parental control.
- Low sense of parental competence.
- Depressive symptomatology.
- Hopelessness vs hope.

<p>—</p> <p>OC: Badly to the point where the emotional reaction is similar to when you were afraid she was dying.</p> <p>Patricia: [cross talk] Yes. Yes. Ja. Ja.</p> <p>OC: Only this time around, it's still the same intense emotions, but I'm wondering if the event is actually as bad as it was when she was having seizures?</p> <p>Patricia: [cross talk] No, it's not. It's not.</p> <p>OC: And there's your key, I think ?(it will help to feel)? a bit less stressed about it.</p> <p>Patricia: Mm. No, you're right. Ja.</p> <p>OC: What did she throw you with again?</p> <p>Patricia: Whatever she gets! (Laughs) Whatever she gets! Whatever is closest. That's why we move things away.</p> <p>OC:</p>	<ul style="list-style-type: none"> • Cognitive restructuring.
--	--

Do you have (noise of something being picked up) stuff like this in your room, in your home?

Patricia:

Oh, no! No! No. It's only in the office now. If I leave that in my room at night, uhm, I'll make sure, because it's on my mind, always! What's gonna happen tomorrow morning? And I put things away. My remotes... We bought so many remotes for the DSTV already; I try to put these things out of the way. If that...

—

OC:

(shuffling noises as he gets up) It's beautiful (inaudible segment) Do you think this is... How bad can she hurt you with this?

Patricia:

Only if the corner hits me.

OC:

Ja. She won't kill you, of course?

Patricia:

No! No, I must realise... I've got to...it's not so much that she's gonna hurt me or kill me. (Noises in background as documents are moved) I'm sc... To get over that feelings, to get over those fears, because why be scared all the time?

OC:

Ja. I-I think it's coming from the time when Sue was actually... her life was in danger.

Patricia:

- Decatastrophising.

Mm.

OC:
And the beliefs are still in your mind, or the belief system's basically that in a way, something catastrophic will happen if she acts out.

Patricia:
(softly) Mm.

OC:
And that is coming from something catastrophic...

Patricia:
[cross talk] Why is that, maybe why I'm fearing the worst is gonna happen to =husband's name=?

OC:
Ja! I think you generalised it to =husband's name=, to =son's name=, uhm...

Patricia:
Like I feel =husband's name= is gonna have a heart attack while she's carrying on like that!

—

Patricia:
Over the years? You see, I manage to duck out of the way, =husband's name= comes forward. He keeps me out of the way. Not so much me. So I do have that; he's there. You know? Like this morning, he was there; he could answer that question only. Over and over I'm ducking, I'm moving to the room.

- Focus on core beliefs of keeping the peace and staying below the radar.

OC:
Mm.

Patricia:
Get away from it. And it helps me.

OC:
Mm.

Patricia:
Because I don't have all that patience to stand there and repeat myself over and over and... ja. It's just dealing with Sue.

OC:
But again, the question is how many times does she throw you stuff?

Patricia:
I can't really count it, I will say... (pause) Big episodes: four, five, maybe ten times.

OC:
Ten times. Has she ever hurt you very, very badly?

Patricia:
Not that I had to end up going to the doctor even. I think the mental side...

OC:
The thought?

Patricia:
Yes, it's the mental side of it.

- Decatastrophising.

OC:

It's the belief.

Patricia:

Ja.

OC:

The belief that she will...

Patricia:

She's scratched me over, and she's thrown me with stuff.

OC:

It is pretty bad!

Patricia:

But there was no stitches, it's just... Ja, it's the mental side of it.

—

Patricia:

[cross talk] It's not that bad! I know.., while I'm thinking about it now. I'm so fearful. I guess nothing happening as I can smile and.., you know?

(Pause) I get so... wound up. It's me, I suppose it's my nature, it's my... nervous system.

OC:

What you're experiencing is extremely valid.

Patricia:

Ja.

OC:

And I mean... I think you have every reason to be fearful of Sue. The question is: will she kill you?

Patricia:

No. I don't think she will kill me.

OC:

But your emotional reaction, I think, might be closer to the worst is about to happen, she might very well kill you. I'm not sure if we have enough evidence of that.

Session 11

Patricia:

It wasn't a bad week at all. I didn't raise my anxiety once for =Sue.

—

Patricia:

And she was happy with that. And I was talking to =friend's name=, Sue is standing next to me, and I say to make-belief =friend's name=: "Yes, =friend's name=, I know you're disappointed, but Sue doesn't feel like going today!"

—

OC:

Where would you rank it for this week? (pause)

Patricia:

You see, with this being a good week and all, it doesn't mean that I'm not stressed.

- Lower levels of parental stress - child's behaviour.
- Dysfunctional parent-child interaction: dishonest towards child.

<p>OC: I'm with you.</p> <p>Patricia: So... ja! Seventy or so?</p> <p>—</p> <p>Patricia: (Sighs heavily) To be honest there's nothing to... Except Sue's good behaviour there's nothing to be... (tremor in voice)</p> <p>—</p> <p>Patricia: (long pause) And looking at Sue, I thank God that she's not worse than what she is. She can bath herself, she can dress herself, and that comes to mind very often.</p> <p>—</p> <p>OC: Have you managed continuing reading a bit [cross talk] (inaudible segment)</p> <p>Patricia: I am doing my reading; I went out yesterday for a day with my friends.</p> <p>OC: Uh-huh?</p> <p>Patricia: And, uhm, what was yesterday? I went on Monday, in the week, for tea. For lunch.</p>	<ul style="list-style-type: none"> • NB: Stress not solely attributed to child's behaviour - suggestion of other stressors. • Significant life event which occurred since last session? • Coping through positive reappraisal. • Coping through distracting herself - not employed before onset of therapy.
--	---

OC:
Mm.

Patricia:
With a friend. So ja.

OC:
Mm. Mm.

Patricia:
It lifts my spirits, ja.

—

Patricia:
(plane flying over office) Uhm, there's other things that are, that's bugging me at home, there is other things...

OC:
Mm.

Patricia:
So maybe if I didn't have that aggravations or stress, I will be, maybe... You know, on a high?

OC:
Ja. Ja. Could you tell me a bit more?

Patricia:
Like =son's name=, for example, he was clean for a long time.

OC:

- Significant and stressful life event: son ?using marijuana.
- Parental stress - other children.

[cross talk] (inaudible segment)

Patricia:

So it looks like he's starting.

—

Patricia:

So of course I am sad. I must say that with my stress levels... isn't so high with Sue, but you've got to look at each and every individual. No! Like I say I could've been worse. I can't, I'm not in control of =son's name's= using. So I remembered that there's nothing I can do about it. Nothing I can do about it! (Long pause)

—

Patricia:

If she's gonna perform now, just think "Agh!" What I'm trying to do, if it does happen, unfortunately (chuckles). It didn't happen this week, but I'm glad nothing happened! If something happens, and she's gonna throw her toys out her cot, I must just try and remember it's not that bad! This is gonna be going a couple of minutes.

—

Patricia:

He must try and remember, if she's gonna go ballistic, say it to yourself, I say to =husband's name=, just say it yourself: In a few minutes it is over! She's not gonna hurt us.

—

- Family stressor (not directly linked with child with ID)
- Helplessness w.r.t. other child.
- External locus of control.
- Cognitive distortion - polarised thinking.

- Cognitive restructured thought w.r.t. child's behaviour: temporality and severity.

- Cognitive restructured thought w.r.t. child's behaviour: temporality and severity.

Patricia:
He just called him and said, come get rid of this. So of course he freaked, and didn't want to. So =husband's name= did it himself. And then he reckons it's..., you know? God put it in the ground.

—

Patricia:
Maybe I'm being spiteful but at this stage of my life I've had children at a young age. I'm still sitting with them and I haven't had a break from them.

—

Patricia:
And that was... we had hidden agendas there.

OC:
Mm.

Patricia:
You know?

OC:
Mm.

Patricia:
No children is coming back home!

OC:
Ja.

Patricia:

- Recalling previous incident when son planted dagga in garden.

- Underlying fear: son will come back to live at home.

- Anger.

So as sad, as sick as it is, it's the way we felt! Especially him, because he'll think it's okay. I can go home to mommy and daddy (tremor in voice). (pause) And I don't want that!

—

Patricia:

Because he's become irresponsible with the stuff. He thinks... there was a time he would come there and think, okay (scratches noises discernible)... he'll probably be so out of it that he couldn't make his way home. And then there was one time she wouldn't open up for him. And he'll come to us. He'll think that he could just come and sleep on the couch. And we put a stop to that! We said we're not having anyone sleeping on our coaches anymore! So he asked me why not? I said because (it is) my furniture!

OC:

Ja.

Patricia:

You're not going to sleep on my fu... And I had to be cruel to be kind. And I said: you're got a home to go to. You (inaudible segment) (tremor in voice) =son's partner's name= don't want to open up for you. Well, I wouldn't open up for you either if you can't go home at a decent hour. Ja! So that is the fear, she's gonna walk out...

—

Patricia:

I have to, I have to, because I've dealt with =son's name=, in his craziness, and I'm not prepared to...

OC:

- Parental stress - son.
- Being assertive towards other children.

[cross talk] Do it again?

Patricia:

...do it again.

OC:

(inaudible segment)

Patricia:

Because that's messed my nerves up for a long time.

—

Patricia: I just don't need my family, my children to be so involved in my life.

OC: Overinvolved?

Patricia: Overinvolved! There're always there. **= [Oother daughter's name]= and her fiancé are there every day. . . And I don't need that. We've had lots of issues about this before, and, uhm, I need my space! (Pause) And to some people it doesn't sound nice . . .

OC:

Mm.

Patricia:

But I said yes, I'm happy when I know they're safe, and they're home, and when I see them once or twice a week it's good! It might not be enough, but I'm... the way I feel now once or twice a week is good. (Sniffs) I want to invite them over for supper, not have them just there now I have to make supper. Make extra supper. (Sniffs, crying?) Ja!

—

- Apprehensive expectation - "He will mess up my nerves again."
- Worry about own mental health.

- Enmeshed family.
- Anger and sadness - other children's relationship with her.
- Perceptions: Being used/exploited by other children.

Patricia:
Ja, so it's like a vicious circle [sic], you know? It's been going on for a long time, and... ja.

OC:
But you shifted? You can't, you don't want this to continue?

Patricia:
Not for a long time, for years now.,

OC:
Ja.

Patricia:
...I've been complaining about the same thing, uhm, ja. It's not only the money, it's his kindness, he's too... It's not called kindness anymore.
Pardon! To me it's not kindness.

OC:
You get to a point, I mean each life developmental stage you're in, has its own requirements.

Patricia:
Mm.

—

OC:
Is he anxious?

Patricia:
He is a very anxious person!

- Conflict with husband w.r.t. their relationship as parents with other children.
- Wish to become more assertive towards her other children.

OC:
You see, that's the problem.

Patricia:
Very, very anxious person. But the stuff that he's smoking, definitely...
(inaudible segment) I mean, it's given him all the reasons, I mean, it
messes up with the mind! The nervous system, it messes up everything.

OC:
Mm.

Patricia:
But he is an anxious person.

OC:
So there's an underlying anxiety not treated?

Patricia:
Ja.

OC:
Uhm, has it been treated before?

Patricia:
Mmm. No.

OC:
He self-medicates.

Patricia:
Mm.

OC:
Mm.

Patricia:
Oh, definitely. And uhm, as the habit becomes stronger, he loses the plot:
“I have to go smoke!” “I can’t do this!” And it’s like chaos!

OC:
Mm.

Patricia:
?(And he’s gone)?

OC:
Self-reinforcement.

Patricia:
Ja. Then he hasn’t got the time of day for his own child! As much as he
loves him... I mean I know it’s part of the disease of-of addiction.

OC:
It’s all-consuming, it takes everything. I mean, that’s-that’s what makes it
so difficult!

Patricia:
Ja.

OC:
Mm. Okay.

Patricia:
(Long pause) Ja, there’s nothing I can do about =son’s name=, but like I
say, I’m supposed to just love him unconditionally (door slammed in

- Mental health of other child.
- Worry about other child.
- Parental stress - son.

background), but I find it very difficult to show that love, you know?

—

Patricia:

Ja! No! No, we'll deal with it. I'll deal with it. If I can't then I'll just go for a walk. I'm not prepared to make myself sick by dealing with it in an ugly way. In his ugly way, where he's gonna perform and shout and scream. (Inaudible segment), for his own way, I'll rather take a walk. I'm not going to upset myself over things that I'm not in control of.

—

Patricia:

And like I did say: I hide all the stuff, the heavy stuff. I don't hide it, I stick it out of the way. So she doesn't always want to hurt us. She does it out of anger, frustration, not that she wants to hurt us. She's always sorry. And she'll... most times she would say: "It wasn't me!" If something's broken, if she put her hand through the window, "It wasn't me, hey?" But the blood. And I'd say: "But look at your hand!" "But it wasn't me!" So... ja.

—

Session 12

OC:

A couple of minutes just to catch your breath and... are things going okay?

Patricia:

(laughs)

OC:

Good! Excellent!

- External locus of control pertaining to child who does not have ID.
- Coping strategies: distancing from son's behaviour.
- Assertive and not accepting responsibility.

- Reattribution of intentionality - NB - therapy?
- Coping with child's behaviour through problem-solving.

Patricia:
I think it is, you know? Because... well, not wonderful, but Sue has been... okay. (Inaudible segment); she's not watching TV in the night... I don't know what's happening! Maybe it's prayer. What's happened is... at eight-eight-eight o'clock she has her medication at night, and the past week, half past eight, quarter to nine: "I'm going to bed now!"

—
Patricia:
You know why it doesn't..? When I watch TV...

OC:
[cross talk] Shame!

Patricia:
I'll say: "When I watch TV in the night...", and now she's all ear, she's listening, I'm saying it so she can hear, "When I watch TV late in the night and I don't switch my TV off, I wake up in the morning and I don't feel nice."

OC:
Okay.

Patricia:
I say I feel so sick and I feel tired, and Sue is looking at me, and she's listening to me, but she's didn't say a word.

—
Patricia:
And I left it. And I said: "No, that's great!" And the next morning I felt

- Child's behaviour - improved.

- Dysfunctional parent-child relationship: deceiving child.

<p>better, because I didn't hear anything throughout the night. I did hear her have a fit, but I didn't hear the music. And it made me feel better; I had a more peaceful night.</p> <p>—</p> <p>Patricia: And I praised her, I said: "You know, Sue, look how good you ?(look)? Look in the mirror! Look at your eyes."</p> <p>—</p> <p>Patricia: So it's been good. Uhm, there's been no outbursts this week. The constant repeating, of course.</p> <p>OC: Ja.</p> <p>Patricia: The constant repeating... A thousand times a day; the same things over and over, which is stressful, but I can... I'm... I can walk away, knowing =husband's name= can listen to it, or... ja. So it wasn't a bad week at all.</p> <p>—</p> <p>Patricia: It's actually... I was actually scared, because when the shit hits the fan...</p> <p>OC: Mm. (Laughs)</p> <p>Patricia:</p>	<ul style="list-style-type: none"> • Higher locus of parental control - child not listening to music in night after management strategy was implemented (see above) • Good parenting behaviour: Positively reinforcing socially-acceptable behaviour (not listening to loud music at night) through praise. • Behavioural outbursts subjectively described as improved; repetitive behaviour persists. • Maternal mental-health: Apprehensive expectation.
--	--

<p>You know, the calm before the storm?</p> <p>—</p> <p>Patricia: I'm going to manage it; I want to manage it the way I learnt to, because it's gonna be easier for me.</p> <p>OC: Mmm.</p> <p>Patricia: I noticed it is easier for me when I change my way of thinking.</p> <p>OC: Mm.</p> <p>Patricia: I'm not gonna think... I want to try not to... I'm not gonna say I'm not going to... I have to try not think the worse [sic].</p> <p>OC: It's while its happening, when-when Sue...</p> <p>Patricia: [cross talk] Ja! When it happens then my brain goes straight to the worst!</p> <p>—</p> <p>OC: ... and go through you mind: Okay, what is about to happen, based on past experience isn't all... It's bad, but it's not...</p>	<ul style="list-style-type: none"> • Modified belief - decatastrophising. • Decatastrophising.
--	--

<p>Patricia: It can't be that bad.</p> <p>OC: It can't be the end of the world.</p> <p>—</p> <p>Patricia: And I can walk away.</p> <p>OC: Ja.</p> <p>Patricia: I always got a feel of Sue coming up behind me; and she does attack from behind... with the fists. You know, but then again how-how much is she gonna hurt me? But I must remember how I never thought of it before that while we're scared. Well, we're scared, but lately I realised: How hard is she gonna hurt me? How much is she gonna hurt me?</p> <p>OC: Mm.</p> <p>Patricia: And I'll try and remember that; I'll have to try and remember that... for my own good. Ja! (sighs heavily)</p> <p>—</p> <p>Patricia: You know, I can't relax as such around her, because even =husband's</p>	<ul style="list-style-type: none">• Decatastrophising and cognitive restructuring.
---	--

name= and I can't even have a conversation. Everybody else can't have a conversation with Sue around.

OC:

Mm. Mm.

Patricia:

Because it's: "Say 'no'! Say 'no'!" I say: "Ohhh, it's a beautiful day!", "Say it nice! Say it nice! Say it nice!" You know?

OC:

Beautiful day.

Patricia:

So you don't have a conversation around her; she's interfering all the time; she's in your face all the time. Uhm, ja.

OC:

Mm. It's pretty hectic. Sjoe! Patricia, if I can just come back here for a second before we move on. Uhm, by actually making it quite explicit what you need from her, number one, and then repeating it, number two: subtle, but in a very real sense and with immediate results; and then (you are) reinforcing the good results. Should she play music again, and turn up the volume, you have to basically ignore that. (People talking in background in corridor).

—

OC:

Mm.

Patricia:

(Door slammed) She does ask me, but if the music was loud I would close

- Constant vigilance - apprehensive expectation about behavioural outbursts present.
- GAD - uncertainty created by constant worrying about behavioural outbursts - trying to repress uncertainty through thought repression.
- Psychoeducation but also summary of work done so far.

<p>my door automatically.</p> <p>OC: Mm.</p> <p>Patricia: ?(Especially)? in the middle of the night.</p> <p>OC: Does it help?</p> <p>Patricia: Ja, it does help a little bit but you can still hear it.</p> <p>OC: Mm.</p> <p>Patricia: You can still hear it and like I said, I tried earphones... earplugs. It doesn't... Not for me. Maybe I want to hear it, I don't know, but I hear it. Because I'm listening out for it.</p> <p>OC: How big is your room?</p> <p>Patricia: A little bit bigger than this.</p> <p>OC: Egg cartons...</p> <p>Patricia: (Sighs) No!</p>	<ul style="list-style-type: none"> Brainstorming ways of lowering intrusive nature of noise during the night.
---	--

OC:
Have you..?

Patricia:
[cross talk] I heard about it! (Chuckles) Imagine me putting... (Laughs loudly).

OC:
(Laughs) It's funny the...

Patricia:
[cross talk] ?(Maybe)?, and if I put it in =daughter's name's= room, it wouldn't work. It wouldn't work in her room, hey?

OC:
It will! It will definitely work. Uhm, it works like magic. I mean, the stuff you find in music rooms are quite expensive. So... and really expensive these days.

Patricia:
Mm.

OC:
But it-it works like magic! It's just not very easy to (inaudible segment)

Patricia:
Ja.

OC:
It looks a bit silly, but it works! (Laughs)

Patricia:

- Humour - alliance stronger when compared with stilted nature of earlier sessions.

<p>If I'm ?(desperate)?... If I really become desperate I think I might try it. If I'm really... (Laughs)</p> <p>OC: [cross talk] (laughs)</p> <p>Patricia: I don't know! I mean, I've tried earplugs.</p> <p>OC: Mm-mm.</p> <p>Patricia: I ?(know you even)? get better than what I've got, but what I got didn't work: the wax, and then the ear plugs. It didn't work.</p> <p>—</p> <p>Patricia: I always didn't want it like that, but he'll say: "Leave it!" He always wanted to keep the peace.</p> <p>OC: Ja.</p> <p>Patricia: But now it's peace... it's peace at the moment. Mm. For now.</p> <p>OC: [cross talk] For the next while.</p> <p>Patricia: Yes.</p>	<ul style="list-style-type: none">• Keep the peace (husband).
--	---

It's no good making myself sick. Over it, I read the letter for the doctor... I haven't been... Maybe I'm in denial, 'cause I don't want medication, but I'm... my sp..., my sister yesterday said to me: "Go..!"

OC:
Mm.

Patricia:

“...to the doctor, get it, you do need it!” She said to me: “You needed it years ago!” I said I just carried on with my life, with all the hazzles, everything, I just carry on because I thought: Agh, I must just accept it; I must just accept it. But she... she also said: “You need something to help you get through.” So I am gonna do it... I haven’t done... I didn’t want to do it.

OC:
Mm, I picked up on it.

Patricia:

I didn't want to do it. But I'm going to go, more or likely tomorrow, or Wednesday for the latest. But I am gonna go!

Instead of stressing out and getting sick and going off my food because I'm upset about this or that or the other. Ja.

OC:
It is difficult. It's difficult because it's Sue, other issues as well.

- Intervention: referring to medical doctor for depression and anxiety.
- Coping by seeking family support from sister.
- Formal support initiative.

- Son not abusing substances - false alarm. Worry caused parental stress, not evidence of event (son using substances) = cognitive variables to parental

Patricia:
Mm.

OC:
And, you know, if your mood goes down, it's very difficult to get it [cross talk] (inaudible segment)

Patricia:
[cross talk] Ja.

OC:
In a sense it's been...

Patricia:
It's been tough. It's been tough! And I was mistaken with =son's name=
I was so...[cross talk] (inaudible segment)

Patricia:
Wednesday evening... Wednesday afternoon we fetch =grandson's name=
from crèche, I phoned =son's partner's name, when are you ?(gonna)?
fetch him (inaudible segment)? Can we fetch =grandson's name= so that
he can come to us for a couple of hours, and then she'll come fetch him
after work. She says not a problem, but will we ask =son's name= to
rather bring him home, otherwise he gets home too late. And then,
(sighs), while I was on the phone I asked how's =son's name= been. She
said, no, wonderful. I said: "Are you sure, =son's partner's name=?" She
says: "I promise you." I said: "Has he been home the weekend, like the
previous weekend?" "Yes, why?" So I said... I told her what my thoughts
were. She says: "No, I promise you..." She says... And then she did say... if
and when it does happen, she says: "I'm out of here!"

stress.

- Coping through problem-solving and confrontive coping -worry w.r.t. son's possible abuse of marijuana.

<p>—</p> <p>Patricia: Mm. Maybe sixty.</p> <p>OC: Sixty. So it has improved a bit?</p> <p>Patricia: Mm.</p> <p>OC: Uhm, and anxiety? Anxiety about Sue; anxiety in general?</p> <p>Patricia: It's still there.</p> <p>OC: Mm.</p> <p>Patricia: I'm still anxious.</p> <p>OC: Ja.</p> <p>Patricia: You know? All the time.</p> <p>OC: Mm.</p> <p>Patricia:</p>	<ul style="list-style-type: none"> • NB: Opportunity missed in therapy: addressing impact of GAD on parenting and parental stress. • Symptom checks.
---	--

<p>Even if it doesn't concern Sue. For... the only thing that's happening.</p> <p>OC: Mm.</p> <p>Patricia: You know, very anxious. I've always been an anxious person.</p> <p>OC: Mm.</p> <p>Patricia: All the years.</p> <p>OC: Mm.</p> <p>Patricia: So that doesn't left [sic] me. So that made me also realise more: I do need something to help me cope.</p> <p>—</p> <p>Patricia: [cross talk] Like when something happens, for example driving here? This truck... wasn't gonna hit us, but I was expecting the worst.</p> <p>OC: Mm.</p> <p>Patricia: You know?</p>	<ul style="list-style-type: none">• Describing symptoms of generalised anxiety.
--	---

OC:
Mm.

Patricia:
And I said to =husband's name=, uhm... I ?(moaned)? at him even when it wasn't his fault.

OC:
Ja.

Patricia:
You know? It's this truck that just came past us.

OC:
Ja.

Patricia:
Big long truck. You know, it was like: how can this happen and I was like
?(already)? nearly under the seat. Nearly under the seat. So that's just
me.

OC:
Mm. How long has it been like that?

Patricia:
All the years. All the years, like I said I was brought up... I was anxious,
very anxious, always looking behind me.

OC:
(speaking very softly) Ja.

- GAD: Worrying about truck - describing self as worrying about everything - worst is bound to happen.

- Discussing anxiety.
- Role of formative influences in early childhood.

<p>Patricia: My brothers were... (inaudible segment), klapped (knocking) me against the head, because I was always... you know? Dysfunctional family.</p> <p>OC: Mm.</p> <p>Patricia: So I was always an anxious person.</p> <p>OC: Yes.</p> <p>Patricia: And then I met =husband's name=, who's cool and calm, you know? (dragging words out with extension of vowels)</p> <p>—</p> <p>Patricia: And I was very scared when she was... You know, anxious all the time! When is she gonna have the next fit? (Door slammed in background) Am I gonna be there? All that, all the years.</p> <p>OC: Mm. Mm. Can you see the correlation? I mean, we spoke about it. But how that, mm, actually conditioned you to be on guard twenty-four hours a day?</p> <p>—</p> <p>Patricia: [cross talk] That's why at the time I had her mattress in my room!</p>	<ul style="list-style-type: none"> • Ascribing child's physical health (epilepsy) as formative influence of her anxiety. • Constant vigilance.
--	--

OC:
Mm.

Patricia:
In case she has a fit. What can I do if Sue has a fit? And a good friend of mine told me that. She said to me: "Sue, what are you going to do? You can't stop that fit! So why you got her in your bedroom? You're not going to get any sleep that way."

OC:
Mm.

Patricia:
"If she's in her own room, you might not hear one or two fits, but you will be able to get some sleep."

OC:
Ja.

Patricia:
"Because you're hearing that, with you being there, what can you do? Just stand there and watch that she doesn't get hurt?"

—
I used to cry; it used to eat me up. I just couldn't handle it, but over the years I realised there's nothing I can do about it. Like I've said, I've got to be strong for Sue, (tremor in voice), I've got to keep going; I can't be upset all of the time because she's having seizures. At the end of the day, I'm not having the seizures, Sue is.

OC:

- Directly describing constant vigilance.

- Role of early parental experiences (seeing child having seizures &

Patricia:
Ja.

I need to work. I can't work if she's at home. Ja! So that was good for me. And that's... at that time my coping mechanism was: have a drink! Drank the coke with work!

OC:

Ja. Ja again, I mean, it makes you feel better. You need 'better'.

Patricia:
Mm. Have a drink!

OC:
[cross talk] (inaudible segment)

Patricia:
Ja! Going to work now, I need to cope! I need a drink to get there. And that's what happened. Ja!

OC:
Mm. Mm. Okay, Sue. No, no, it-it's been a tough journey, but here you are, fifty two, the future now? What's laying ahead for you?

Patricia:
I do feel hopeful, maybe because... because it's been a nice week. If it was a crap week I wouldn't be sitting here saying I feel hopeful. Then I'll

- Coping with earlier experiences by abusing substances. - self-medication.

probably be very emotional.

OC:

Mm. Ja. Ja.

Patricia:

But because it's been a nice week... makes me realise it's not always doom and gloom. And it's crappy to have to deal with it, but like I say, I just so used to dealing with the shit.

—

Patricia:

So... ja, I would just want Sue to be in a good place... good place, where she's looked after, and for peace in my life. And that's all I want.

OC:

I'm optimistic about it, carefully optimistic, based on two things. Uhm, and believe me we work with this every day all day and people don't get in. So I'm supposed to be much more negative.

Patricia:

Mm.

OC:

I'm optimistic due to the following reasons: number one, =service for people with intellectual disability= knows Sue. And they manage Sue's behaviour. So I can see somebody like =housemother's name= of =group home's name= being able to manage Sue's name's behaviour.

—

- Hope (vs hopelessness)

- Focus on future of child.
- Group home placement.

Patricia:

[cross talk] You know what we did find, also that made me think this week, I thought about it the last time. Why is it so peaceful, nice? (Door slammed in corridor) Because we've been alone with Sue most of the time. (Pause) =Other daughter's name=, and =other daughter's fiancé's name= and =son's name= was hardly there this week. So I don't know if I'm right or wrong, but I feel like it because there was no interferences. Everything was routine.

—

Patricia:

Ja. He just came back. Ja.

OC:

?(Sailor)?

Patricia:

Yeah, he is loud; he means well. I don't really... I can't say I don't like him, but I...

OC:

You tolerate him, [cross talk] [(inaudible segment) from the previous session, yes.

Patricia:

Ja. Ja. I tolerate him, because =other daughter's name's= happy with him. He's never been rude to us or disrespectful. He's been a little bit disrespectful, but that's just his way. But he hasn't been rude to us. (noise in background of gum being unwrapped) I tolerate =other daughter's fiancé's name=; he means well. He does try to help where he can, but like I said this week, he could be also more peaceful at home. Uhm... ja. Peaceful by quiet. =Other daughter's name= is loud; =other

- Parental stress due to other daughter.

- Lack of family support - other daughter and her fiancé not assisting in low arousal environment - complicating caregiving.

<p>daughter's fiancé's name= is loud.</p> <p>OC: Mm.</p> <p>Patricia: (inaudible segment) screaming. They're talking loud, and laughing, and carrying on, and Sue likes quiet. There was a time in =daughter's name's= life she liked a lot of people. And party. Playing music. No more. For a couple of years now, =daughter's name's=... Invites people around, but she's not even in the company.</p> <p>OC: Mm.</p> <p>Patricia: So she likes... I noticed what she likes is the quietness. It must be there, but quiet. She doesn't like excitement and things like that anymore. When she was younger she did.</p> <p>—</p> <p>OC: I'm very impressed with you and =husband's name's= expressed emotion. The fact that it's not high. It's not like: "Ooh, Sue, what are you doing?"; "No, you can't do that!"</p> <p>Patricia: Mm-mm. Mm. Mm.</p> <p>OC: Is it the same with you children though? I mean, do they also have low expressed emotion? Or do they tend to make a bit more of a running</p>	<ul style="list-style-type: none"> • (Low expressed emotion in contrast to earlier statements Patricia made about high expressed emotion from children). • Problem- other children makes too much noise.
--	--

commentary when it comes to Sue's=? behaviour. What's the deal with them?

Patricia:

Uhm. They cut zip. They say nothing.

OC:

Do they say nothing? Good!

Patricia:

It's best that they say nothing.

OC:

Yes!

Patricia:

[cross talk] But we told, =husband's name= (inaudible segment)... But he always said: Don't interfere! You can't deal with it; you don't know how to deal with it; don't interfere.

—

OC:

You have many ducks in a row! So I mean, I don't think there's enough acknowledgement of that. And there's quite a bit of structure; there's consistency in the way of managing Sue's behaviour, which is great. There's low expressed emotion. Wonderful. Uhm, and you are gently challenging her now.

Patricia:

Mm. Mm.

—

- Low arousal environment - many good practices already in place.

<p>Patricia: I've been telling my kids this for many years, a good few years.</p> <p>OC: Mm.</p> <p>Patricia: "I want to invite you for supper." Not just rock up! It's upsetting for me, because I might have made the food already for the evening.</p> <p>OC: [cross talk] (Inaudible segment)</p> <p>Patricia: Now another two or three or four walks in, what do I do?</p> <p>OC: Mm.</p> <p>Patricia: I tell them: "As much as I love you, I don't want to see you every day!"</p> <p>OC: Mm.</p> <p>Patricia: This I've been telling =other daughter's name= for a long time! And visit me, but don't come eight o'clock the morning until eight o'clock the night. I don't need it, I need my space. But they do know these things...</p> <p>OC: Mm.</p>	<ul style="list-style-type: none"> • Children experienced as being enmeshed. • P assertive with healthy boundaries.
--	---

<p>Patricia: Sometimes they do still try and overstep the boundary, but I'll just let them know. And this past week was good, because they did know, they did realise that I do know, I reminded them again last week, that I need my space. So... ja.</p> <p>OC: And excellent! And as supportive as =husband's name= is, my sense was that... [cross talk]</p> <p>Patricia: [cross talk] He's not that supportive like that!</p> <p>OC: [cross talk] ?(Like that)?</p> <p>Patricia: He actually was missing =grandchild's name=, the little one.</p> <p>OC: Mm.</p> <p>Patricia: This past week. He really was missing =grandchild's name=, because he didn't see =grandchild's name= for four days. And, uhm, I knew he was missing =grandchild's name=, and I said to him: "Don't you want to go visit =other daughter's name=?"</p> <p>—</p> <p>Patricia: [cross talk] Mm. It's there. It's there. In your face.</p> <p>OC:</p>	
--	--

Ja. Uhm, you need to-to make certain allowances in the environment.
And I think, you know, the holy grail has been through the last number of years is to keep the peace.

Patricia:
Mm.

OC:
And maybe if you could just slightly adjust that one with =husband's name=...

Patricia:
Mm.

OC:
...to make it to 'keep the peace and quiet.' , I think it is absolutely...

Patricia:
Definitely, definitely! I found that out when it does work.

OC:
Ja.

Patricia:
It has to be that way.

OC:
Ja! The expressed emotion is covered, so I'm not even going to mention it.
It's wonderful that you've covered that. So that's maybe the first thing to think about; is to try and make things quiet.

Patricia:
Mm.

- Discussion of management of child's behaviour

OC:
I do think you need to, number two, gently challenge, uhm, the things that you know... The policy about =daughter's name.= If-if music, playing music in the evening, through the night, you can't sleep. It is unreasonable.

—
OC:
Keep on reinforcing it every time it happens. Praise her.

Patricia:
Mm.

OC:
Then gradually you start withholding the praise, and you fade it, as they call it in behavioural language. So, uhm...

Patricia:
[cross talk] What?

OC:
... maybe for the next week, or two weeks, you keep on praising her every day.

Patricia:
Mm.

OC:
And then the following week, you only praise her every second time.

Patricia:
Ja, what I've done this... Sorry! What I've done was buying her... giving her

- Focusing on future management of child's behaviour: reinforcing elementary positive programming (p.71)

something every day... (Pause) ... which I realise I can't keep on doing. I was...[cross talk]

Patricia:

One day it was a spray, and the underarm spray. And then the next day was... Well, you won't believe what her dressing table looks like, but anyway! The next day it was a bubble bath. The next day it was a... I thought, okay, she's got like four bubble baths already! Something else but she wants toiletries. So I bought her a... a hand wash in a container. Uhm... (sighs) Friday it was two balls of wool. Saturday was nothing. Sunday was nothing. And today she wants another two balls of wool. So I thought I'll say: "Okay, I'll get you wool but I'm not gonna get the same colours..,"

Patricia:

The whole week. But the things that she wants is just like adding to what she's got. I think she's got six sprays on her dressing table, different underarm sprays. She's got like six roll-ons; I don't know how many bubble baths; and then it's powders. She's got all the stuff, so I might be wrong, (inaudible segment) go to stop, wanting to buy her stuff to... (Inaudible segment) buy her, if I had it I'll give it to her. It's just like trying to coax her into being staying good. (Coughs) So that's what I have also been doing, so I don't know if it is the right thing to do. It's worked!

OC:

But there were two reinforcers then. One is tangible, material reinforcer;

- Positive behaviour towards child ; positive experience: P used positive reinforcement during last week
- Behaviour of child: Autism-related problem behaviour.
- Skills training and psychoeducation: differential reinforcement.

and the other one was the social reinforcement.

Patricia:

Mm.

OC:

Praising her. Now, social reinforcement is by far the most powerful one.

Patricia:

Mm.

OC:

So Sue is really going for that as well. We know that.

Patricia:

Mm. Ja.

OC:

Uhm, if you start to reinforce her, it needs to be done consistently every time the desired behaviour...

—

Patricia:

I'm gonna do it. Because it over, it's (inaudible segment, mumbling) ...they can't also, I feel bad... not having them there; they're not used to only by appointment, you know? So then they do pop in, they do see my face (sighs heavily), I'm not too happy. I mean, it's ?(obvious)?, I can't hide it, but, uhm, I try to hide it but... ja, I will work on it, I have... I must work on it for my own sanity as well as peace at home.

—

- Parental stress and depressive symptoms due to behaviour of other children.

Patricia:
And you'll say to them: "You're upsetting the apple cart!"

—

Patricia:
And you'll say to them: "You're upsetting the apple cart!"

—

Session 13

Patricia:
So that's where =husband's name=... And I've been to doctor, so that's sorted. [cross talk] (inaudible segment)

OC:
[cross talk] What did the doctor do?

Patricia:
No, I gave him the letter.

OC:
Ah-uh?

Patricia:
And before I gave him the letter, I told him where I am at the moment, about Sue. Then I gave him the letter. So he says: "Okay, fine... You do need something." I said to him the same story I told you. He said: Not to worry! It's not gonna be addictive.

—

- Lack of family support - other children compromising or working against parental behavioural management strategies.
- Coping through accepting responsibility, confrontive coping and problem-solving - went to doctor:

Patricia:
[cross talk] And my doctor does know my history.

OC:
Ja.

Patricia:
So he knows I can't take anything that's addictive.

OC:
Yeah.

Patricia:
Ja.

—

Patricia:
I knew all about her moving, and I knew that =other daughter's fiancé's name= was called out to sea, and =husband's name's= is gonna have to help. And =husband's name= was going to town on Friday morning, and he said to me: "Make your appointment with the doctor for as late as possible." In the day. Well, I said: "I'm gonna take a ride with you. I need to get out of the house." Because I know after town he's going to =suburb's name=, and we can go for a piece of fish for lunch! So with doing that; on our way home he said to me: "I need to stop of by =other daughter's name=." I don't know for what... what it was for? Something to do with her moving; discuss with her what's gonna happen and blah-blah-blah. Like Saturday morning?(with the move)? Straightaway my stomach... I started feel nauseous.

- Fear of addiction and worry about going to doctor.

- Generalised anxiety about everyday event - helping child with move.
- Significant life event.
- Stressful event outside of parenting context of child with ID.

Patricia:
Just the thought; I said: does he really have to go there? So he says yes.
It's like facing up to it, and then I walked into her flat.

OC:
Ja.

Patricia:
And saw all the boxes.

OC:
What was going through your mind when saw..?

Patricia:
Chaos, chaos!

OC:
Chaos.

Patricia:
I can't handle chaos.

OC:
I ca... There's a thought: I can't handle chaos. What were you facing?

Patricia:
[cross talk] Ja, what also gets me every... The thing is like this: How am I gonna cope with the moving; Sue will on the one side; I'm going to have to look after =grandchild's name= while they're busy moving.

- Anxiety - event outside parenting - child with ID.
- Maternal mental health.

- Automatic thought: I will not be able to cope with this -inferential thinking.

—
Patricia: *Pap!* (drained) Just want to curl up in a ball and die (tremor in voice noted) Not physically die, but... [cross talk] (inaudible segment)

—
Patricia:
Ja! So I try to do what I needed to do by minimising it and saying to myself: It's not that bad! But the feeling doesn't go. Like that arghh! – feeling doesn't go.

—
Patricia:
Then one of us must quickly turn the volume down and then it was okay, I could handle it. And then this morning, =grandson's name= was riding his truck; pushing his truck which makes like a (clears throat) grinding noise. Sue said: "Stop it, =grandson's name=! Stop it! Put that thing away! Put it away! Put it away!" And then she started crying. So I said to =other daughter's name=: "Please take that truck away from =grandson's name=." "Yeah, but he's gonna cry." I said, "I'm sorry. I feel sorry for =grandson's name= now, but ..."

OC:
Okay?

Patricia:
"...take it away. Can you see what is happening? It's the sound." I wasn't

- Depressive symptoms - tired, helpless

- Cognitive distortion - emotional reasoning.

- Responding to cue that might trigger child's behavioural outbursts, feeling guilty because it was at considered as unreasonable towards grandchild - double bind?
- Child's behavioural problems - auditory perceptual problems.

sure, but I said to =other daughter's name= I think it's the sound that was upsetting Sue, because it was grrrrrrrr! Grrrr! Grrr! Loud all the time. And she was sitting there with her knitting, watching the TV. So =other daughter's name= took the tru-truck away, =grandson's name= screaming, Sue is crying and then she said: "I don't feel well! I'm not going to work." I thought: Okay, I'm not gonna upset myself. I'm not gonna upset myself; I thought I'm not going to cope so lekker (nicely) today, but God doesn't give me too much to handle. =Other daughter's name= is making signs at me: She must go, she must go!

—
Patricia:

"I feel like giving you a blerrie (bloody) hiding! Like hit the head of your shoulders!" I used to say those things because I'm angry, and =other daughter's name= was saying this to me now! And I say: "No, =other daughter's name=" And I tried to explain to =other daughter's name= what could be going on in Sue's head from what I've learnt!

OC:
Mm.

Patricia:

And she just looked at me. She says: "Ja, it can make sense." So it did help this morning.

OC:
[cross talk] Okay. Okay.

Patricia:

As pap as I was feeling, I tried to help, and I didn't ?(let it get up)? ; didn't let it get to me.

- Changing from confrontive coping to problem-focused coping.
- Maternal anger - now less?

<p>—</p> <p>OC: It's not intentional in the way of... [cross talk] (inaudible segment)</p> <p>Patricia: [cross talk] That's what I said to =other daughter's name=: "She's not nasty to =grandson's name=, she loves =grandson's name= to bits.</p> <p>OC: Mm.</p> <p>Patricia: She's not being nasty to him.</p> <p>—</p> <p>Patricia: She couldn't handle the... (inaudible segment)... crinched.</p> <p>OC: So it's about this: that for us, you hear a train coming. (mimicks sound of stream train) And it gets louder. But they're much more sensitive to sound.</p> <p>Patricia: Mm. Mm.</p> <p>OC: So...</p> <p>Patricia: That's what I think it is. Definitely. [cross talk] Well it definitely is.</p>	<ul style="list-style-type: none"> • Empathy towards Sue.
--	--

OC:
[cross talk] (mimicking train wheels on line) Ja!

Patricia:
Definitely is.

OC:
And that's common in autism.

—

OC:
Have you noticed that the behaviour has improved?

Patricia:
Yes! It has. Like I said it was two good weeks.

OC:
Mm.

Patricia:
Change.... Sorry, changing again on... Sunday. (phone ringing in background) Ja. It's not unbearable, like this morning, I was feeling normal, healthy and well. I would've probably handled it in the same way.

OC:
Mm.

Patricia:
You know? I did learn, I had learnt that... Ja, just deal with it as it comes and be patient...

- Psychoeducation - hyperacusis.

- Cognitive restructuring: Decatastrophising - self-talk whilst event is taking place; whilst behavioural outburst is taking place or when anticipating behavioural outburst.

OC:
Mm.

Patricia:
...and realise: I must keep on remembering it's not that bad.

OC:
Your mood? I mean your mood in the last week, has it stayed the same?
Has it gone down? Has it gone up?

—

Patricia:
My biggest anxiety is Sue! In life, my biggest thing is Sue.

OC:
Mm.

Patricia:
And other little things trigger it off...

OC:
Ja.

Patricia:
... and I gotta deal with Sue as well as the other crap. That's what I don't want anymore!

OC:
Ja

Patricia:
I mean, I say I don't want to (inaudible segment), but I...

- Parental stress and most of her stress in general attributed to child's behaviour.

OC:
Fed-up?

Patricia:
Ja, but speaking to =husband's name= this morning too, he's got his issues with the work, and blah-blah-blah; and I'm feeling like crap and I said to him, you know, I suppose this is just life. We gotta deal with it. (Pause

—

Patricia:
That's what my kids are telling me; that's what =husband's name= is telling me. Every time something happens. If =son's fiancé's name= says: "Sue, can I give =grandson's name's= birthday party by your place?" Ooh, I feel like...

OC:
Yeah.

Patricia:
I say: "Ja, sure", not happily. And drawing closer to the time, I'm vomiting and...

OC:
You're really anxious.

Patricia:
Mm. That's what happens! And it doesn't have to be like that!

—

Patricia:

- Worry about everyday event - generalised anxiety.

Ja, but it's not that I want... Not that it gives me the urge to want and have a drink, or I'm scared I'm gonna have a drink, because I know what to do before I do have a drink. It's not only that it's just the upsetment of everything. Like the routine. I need routine. Now there's gonna be no routine for a while; things are gonna be chaos. (sighs) I don't know! It just happens; every time something happens, Sue gets sick!

—

Patricia:

Mm. But I... like I know it's gonna pass. It's gonna pass. I know it's gonna pass. Because as before I also felt like it's ... by just talking about it, it's making me feel a little bit better. And before it is... it does pass! I always used to say: this too shall pass. This too shall pass. So that's a...

OC:

It will.

Patricia:

Ja. (Long pause) And then after a couple of days I'm feeling okay again. I know it's just a.., you know, to deal with it and get through it and hope and pray it never happens, you know?

—

Patricia:

So he helped her by getting his guys and supervising while she was at the house... unpacking with her... nie... with her cousin, sorry my nieces, her cousin was helping her unpack. Because I wouldn't be able to physically help her with my chest.

OC:

Mm. Mm. Mm. It makes sense.

- Fear - drinking again - theme.
- Cognitive distortion: Things will be chaos - overgeneralisation - it only relates to her moving.

- Maternal resilience.
- Positive automatic thought: this too shall pass.

- Maternal physical health - emphysema as stressful and upsetting.

Patricia:
And that also upsets me.

Patricia:
Because I can't help like I... you know, want to help. It upsets me a hell of a lot to do physical things I cannot do! As much as I want to. You know, I've always been (a) people pleaser, and lately I can't even hang out a curtain for her.

—

OC:
I must be there all the time. (Long pause) 'Must' and 'all the time'.

Patricia:
And I'm not gonna cope... This is what's going in my mind: Oh God! Straightaway, I'm not gonna cope and I get lam (left without energy).

OC:
Mm.

Patricia:
I get sick.

—

Patricia:
I want to be there, but I don't want to be there! So if I could cope better I would jump in and help Sue as much as I can, but I can't do it! I can't do the physical things!

- Perceptions of helplessness and uselessness because of physical health concerns. Leads to anxiety and stress.

<p>—</p> <p>Patricia: Got to put down boundaries as far as those kids are. But he's not doing it.</p> <p>OC: Mm.</p> <p>Patricia: Not as it should be. He's trying, but he's... They're clever... (laughs) They're clever.</p> <p>—</p> <p>Patricia: She's been aspris (doing something on purpose).</p> <p>OC: Mm-mm.</p> <p>Patricia: She's not. She definitely isn't.</p> <p>OC: If she's aspris, it-it comes down to being aspris... Uhm, I want (to) almost like use a metaphor. It's like you only have four cards where you should have twelve. So if you're aspris based on the four cards, it doesn't really mean that you're aspris. It means that you don't have enough to actually make informed decisions.</p> <p>Patricia: [cross talk] Mm. Mm. Mm. If she cannot make informed decisions?</p>	<ul style="list-style-type: none">• Dissatisfaction with husband about "spoiling" other children.• Reattribtution of intentionality (intent behind child's behaviour)
--	--

<p>OC: [cross talk] (Inaudible segment) Not always. It's not the intellectual disability, it's the autism.</p> <p>Patricia: Mm.</p> <p>OC: So she struggles to regulate.</p> <p>Patricia: Ja!</p> <p>OC: She struggles to... in a social situation... I mean, my partner's kids play WII and sometimes the volume is 40-50 on the television.</p> <p>Patricia: Mm.</p> <p>OC: I'm able to go and say: "Listen guys, pleeease turn the volume down."</p> <p>Patricia: Ja! Ja!</p> <p>OC: But we can do that! For Sue that's incredibly difficult.</p> <p>Patricia: Oooh, I know.</p> <p>OC:</p>	
--	--

<p>It's just noise. (clapping hands) There we go.</p> <p>Patricia: Ja. So we're managing now to: "Put it a bit softer! (whispering)</p> <p>OC: Yeah.</p> <p>Patricia: Whisper to her: "Put it a bit softer!"</p>	
--	--